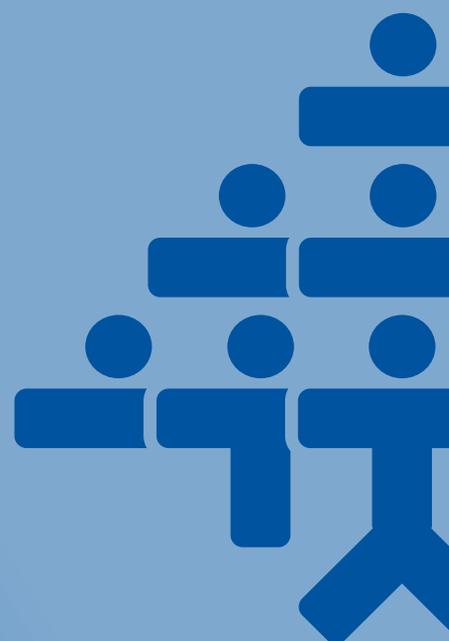


A survey of GP experience with the work of the National Cancer Control Programme and their views in relation to service priorities

AUTHORS

*Marié T O'Shea and Claire Collins,
Irish College of General Practitioners*

APRIL 2016



Foreword

The National Cancer Control Programme is delighted to welcome this Irish College of General Practitioners report, which examines the experience of general practitioners with the work of the NCCP and identifies priorities of the GP community in relation to cancer care. The opinion of the GP community is crucial to informing the priorities of the NCCP and the recommendations of the new Cancer Strategy 2016—2026.

We are grateful to GPs for their support of the National Cancer Control Programme. The vast majority of GPs surveyed consider the organisation of cancer services into designated cancer centres as a positive step and rate the NCCP national GP referral guidelines and rapid access clinics favourably.

This report shows that progress has been made since the 2006 ICGP/ ICS 'Early detection of cancer: a needs assessment of general practitioners' report. However, there remains much more to be done, in particular on increasing patient awareness, improving direct GP access to diagnostics and further development of rapid access clinics for suspected cancer with referral criteria. Other key areas of need identified include guidance on family risk and the emerging role of cancer survivorship.

We look forward to ongoing collaboration with the ICGP to ensure continued improvements in the care of cancer patients and their families.

Yours sincerely,



Dr. Jerome Coffey MD FRCPI FRCR FFRRCSI

Director, National Cancer Control Programme

Acknowledgements

This research would not have been possible without the co-operation of a large number of individuals. We wish to express our thanks to all who participated in the study, with a particular mention to the GPs who responded to the survey.

We want to thank our Advisory Committee members Dr. Regina Codd, Dr. Amanda Daly, Dr. Nicola Elmer and Dr. Marie Laffoy who assisted in various ways with the planning and conduct of the study and who provided valuable feedback on earlier drafts of the study's findings.

The views expressed in this report are those of the authors and do not necessarily reflect the views or policies of the sponsors.

TABLE OF CONTENTS

Executive Summary	2
Introduction	4
Cancer mortality	
Cancer survival trends	
The role of the GP	
Familial risk of cancer	
Cancer survivorship	
Co-morbidity	
The National Cancer Control Programme	
Methodology	10
Aims and objectives	
Study design	
Data analysis	
Findings	11
Section 1: Demographics and Respondent Profiles	
Section 2: Referrals	
Section 3: Other cancers	
Section 4: Targeted assessment of 'high risk individuals'	
Section 5: Cancer survivorship	
Discussion and Recommendations	27
References	29

Executive Summary

The National Cancer Control Programme (NCCP) was established in 2007 to implement the recommendations of the 2nd National Cancer Forum's report 'A Strategy for Cancer Control in Ireland 2006'. At the time, in 2006, the delivery of cancer services in Ireland was described as fragmented and not following best practice. The decision was made to centralise cancer care to eight designated cancer centres. In 2007, the ICGP published the findings of its study 'Barriers to Early Diagnosis of Cancer in Primary Care: A Needs Assessment of GPs' (Daly and Collins, 2007). The Community Oncology Programme of the NCCP was established in 2008. The key objectives were directly informed by the findings of the study.

Aims and objectives of study

The aim of this survey was to obtain the views and experiences of Irish general practitioners in relation to the work of the National Cancer Care Programme (NCCP) over the past seven years and gain their opinions in relation to the future priorities of the NCCP which would assist them in their work.

Methods

A project advisory group was convened to oversee the research between the ICGP and the NCCP. A questionnaire was designed based on the original ICGP/Irish Cancer Society 'Early detection of cancer: a needs assessment of general practitioners' study carried out in 2006 and published in 2007. Data collection was through the use of postal questionnaires. A total of 514 completed surveys were included in the final analysis, a response rate of 18.2%. The study demographics are consistent with the overall ICGP membership population (ICGP, 2015).

Summary of findings

- The vast majority of GPs considered the organisation of cancer services into designated cancer centres as a positive step.
- 57.1% of GPs reported that they 'always' or 'often' used electronic referral.
- The majority of GPs reported that urgent patients with acute symptoms requiring treatment were seen on the 'same day' as referral, a substantial increase on 2007 figures.
- Patients with a new clinically obvious cancer most commonly had a waiting period of between one day and two weeks for assessment.
- 84% of GPs reported that patients with a new clinically suspected cancer were waiting six weeks for assessment.
- Nearly 60% reported that patients with non-specific symptoms with a modest possibility of cancer had a waiting time of six weeks or more for assessment.
- Half of the respondents reported that 50% of patients with a previous history of cancer with a non-specific symptom of cancer were waiting six weeks or over for assessment.
- Approximately 47% of GPs had access to a fast track system (e.g. rapid access clinic) for 'urgent' referrals. Just over one fifth had similar access for any patient with suspected cancer.

- Nearly 60% of GPs reported that they *did not have* key contact details at their local hospital(s) with regards to investigation or referral for a patient with suspected cancer.
- Just over 69% of GPs reported having delayed investigation and 64.8% having delayed referral of patients with suspected cancer due to difficulty in accessing services.
- Over four fifths of GPs reported having sent patients to A&E to bypass difficulties in accessing services.
- A little more than half of GPs considered that they did not have the information they need to assess patients with regard to their individual risk of cancer.
- Approximately four out of five GPs reported that patients with a family history of potentially hereditary cancers (e.g. breast, ovary, colorectal) request genetic testing.
- The majority of GPs reported that they did not have sufficient information to discuss genetic testing with patients.
- Nearly 60% of GPs indicated that they would like to receive further education in the area of cancer survivorship.
- Approximately two-thirds of GPs reported that ‘cancer rehabilitation programmes’ were not available to their GMS (66.5%) or private patients (60%).

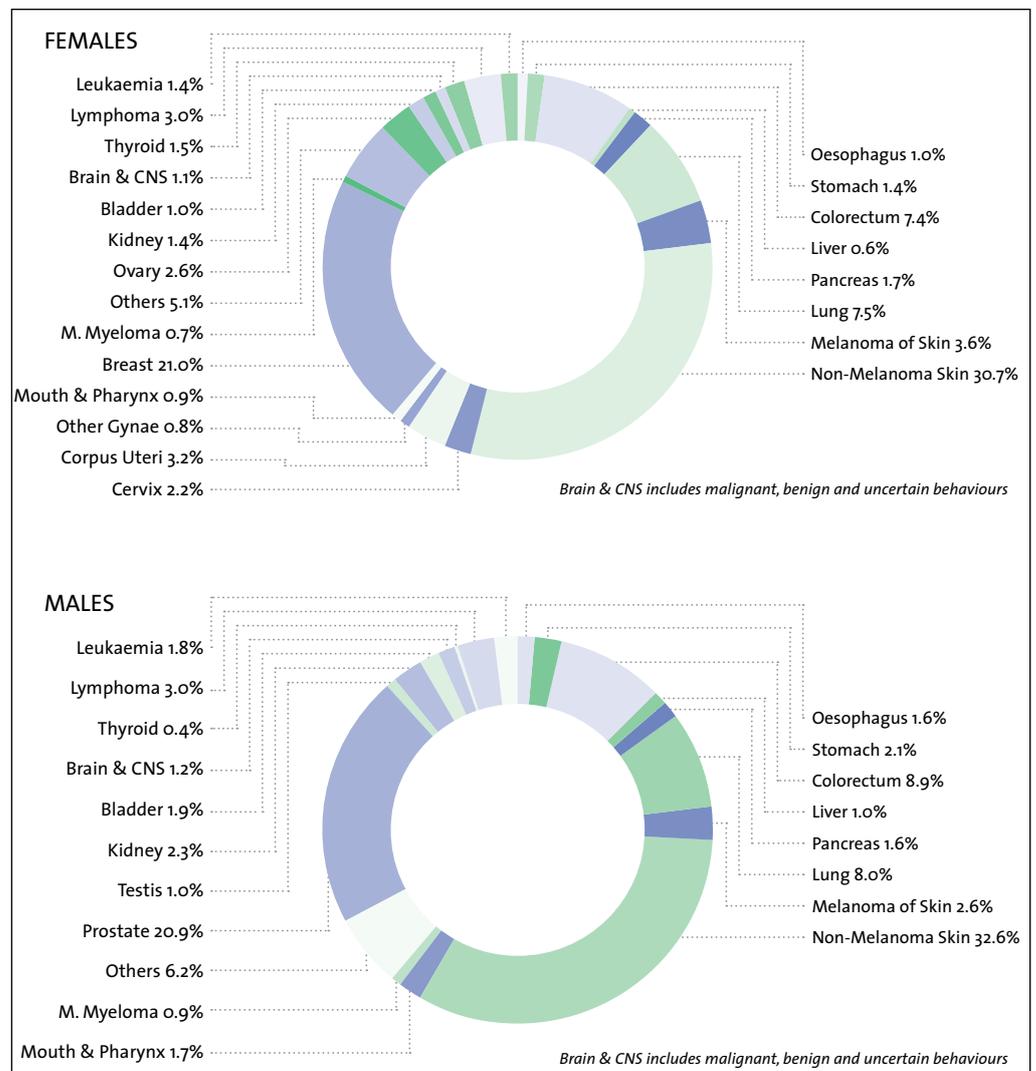
Conclusion

This survey provides some insight into the current situation with regard to cancer detection, investigation and treatment from a GP perspective. The results point to some key actions points for both the NCCP and ICGP but also for other stakeholders in the health care system in Ireland, specifically in relation to guidelines, access to diagnostics, resources and cancer awareness programmes.

Introduction

In Ireland, one in three men and one in four women will develop cancer at some time in their lives. The most recent complete data (2011—2013) from the National Cancer Registry indicates that on average 37,000 newly diagnosed tumours were registered per annum. Of these, approximately 30,000 involved invasive cancers other than less aggressive non melanoma skin cancers. Over half of the invasive cancer tumours diagnosed involved the four most common major malignancies; prostate (3,400 cases p.a.), breast (2,917), colorectum (2,460) and lung and trachea (2,318) (NCRI, 2015). In 2012, age-standardised incidence rates of cancer were considered to be 10% higher than the European Union average for men and 16% higher than the EU average for women; in particular higher rates were recorded for colorectal, prostate, breast and female lung cancer.

Fig. 1. Relative frequency of the most common invasive cancers (including non-melanoma skin cancer) diagnosed: 2011-2013

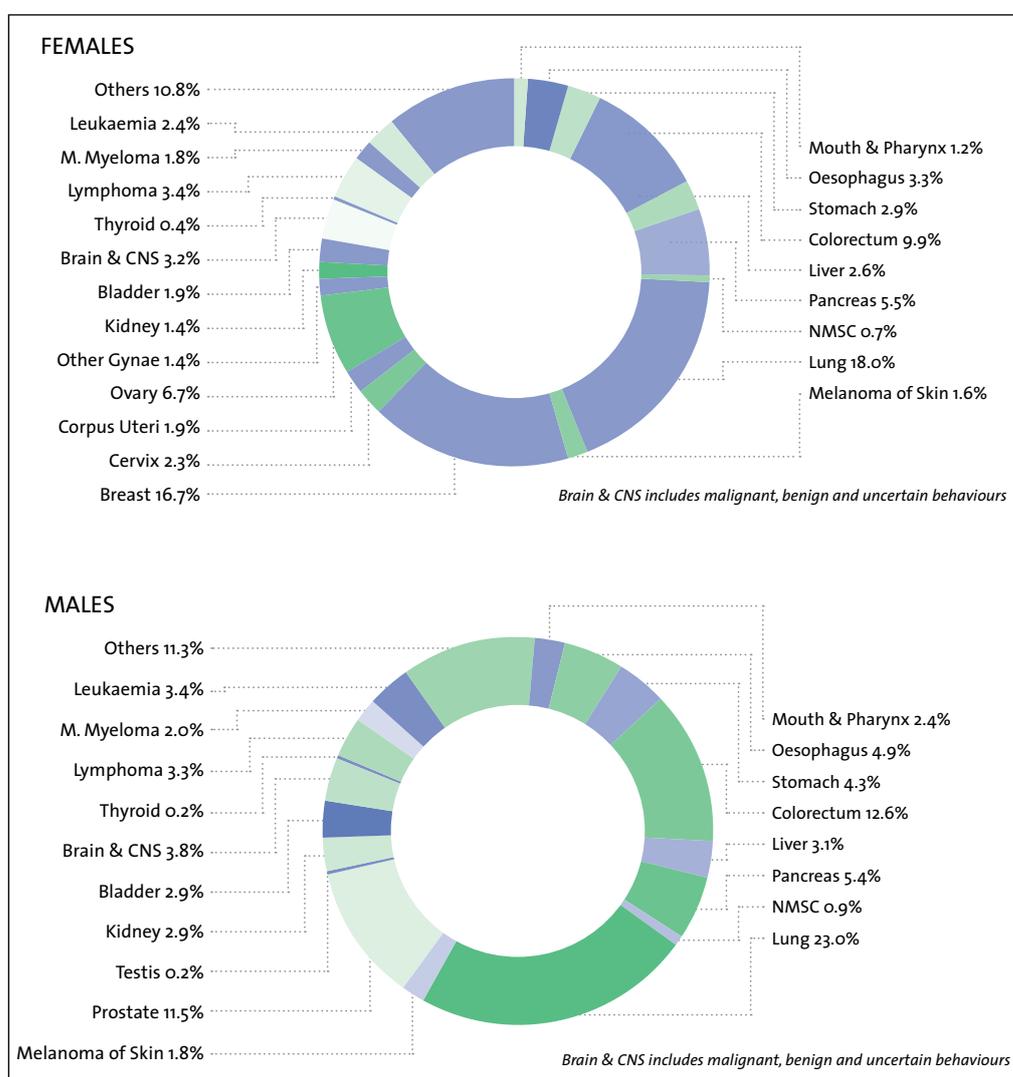


*Figures provided by the NCRI (ncri.ie)

Cancer mortality

In Ireland, cancer is the second most common cause of death, after diseases of the circulatory system. Between 2011 and 2012, deaths from cancer averaged approximately 8,827 deaths per annum, representing 30% of all deaths during this period. On average, age standardised rates of cancer mortality are 37% higher in men than in women. The cumulative risk of death from cancer is one in eight for males and one in ten for females. Lung cancer is now the leading cause of cancer death in both men and women in Ireland, resulting in approximately 1,826 deaths annually. Deaths from colorectal (1,000 p.a.), breast (698 p.a.), prostate (541 p.a.) and pancreatic (477 p.a.) are the next most common.

Fig. 2. Relative frequency of the most common cancer deaths: 2011-2012



*Figures provided by the NCRI (ncri.ie)

Cancer survival trends

Trends in cancer mortality reflect changes in both cancer incidence and survival. Survival estimates for most cancer types in Ireland have improved over time, although this positive trend is clearer for some cancers more than others.

Significant improvements have been seen in colorectal, breast, kidney, testicular and prostate cancers and for multiple myeloma, lymphoma and leukaemia. The CONCORD-2 study indicates that across ten major cancer types, Ireland is approximately mid-way in the ranking of survival estimates among European countries (Banks et al, 2014).

The need for effective cancer care is amplified by the fact that the incidence and prevalence of cancer is expected to increase worldwide by at least 65% over the next twenty years. The World Health Organisation (WHO) predicts that cancer will result in 12 million deaths by 2030 (WHO, 2011). In an Irish context, cancer incidence is expected to double in the Republic of Ireland by 2040. This increase is linked with improvements in detection and diagnosis and the growing and aging population (ncri.ie). The economic value of early diagnosis is evident, with treatment for early stage cancer in the majority of cases found to be more cost-effective than later stage cancer (Cancer Research UK, 2014). In Ireland, the economic impact of cancer over one year (2009) was approximately €1.4 billion, the fifth highest in Europe (Luengo-Fernandez et al, 2013).

The role of the GP

More than 200 types of cancer are known to exist and signs and symptoms are often inexact. Approximately 85% of patients with suspected cancer present initially to their general practitioner (GP) prior to being seen in a secondary care setting (Allgar and Neal, 2005; Banks et al, 2014). In the UK, a GP with approximately 2,000 patients typically sees six to eight new cases per year (Rubin et al, 2015). However, differentiation between patients whose symptoms may be due to cancer and the much larger number of patients with similar symptoms arising from other causes represents a considerable challenge to GPs. Aggressive forms of cancers can cause symptoms which are likely to be identified earlier, with less favourable prognosis, however slower forms of cancer can lead to delays in detection due to the multi-faceted and ambiguous symptoms they present (Redaniel et al, 2015).

Early diagnosis is one of the primary ways to increase cancer survival rates, and timing of diagnosis is a crucial element for positive treatment outcomes (Banks et al, 2014; Richards, 2009). Research has suggested that patients require at least three consultations with their GP before a possible cancer diagnosis is reached (Thomson and Forman, 2009). A primary risk factor associated with patient delay in presenting with suspected common cancers is the lack of awareness of symptoms and delays in presentation for consultations (Jensen et al, 2014; McLPatrick et al, 2013; Vedsted and Olesen, 2011). Patients with cancer are found to initially present to their GP with low positive predictive features and symptoms (Rubin et al, 2015; Hamilton, 2009). Additionally, the most commonplace symptoms of cancer are also frequently associated with other diseases (Banks et al, 2014). Therefore it is essential that there is suitable access to appropriate services for cancer detection and diagnosis.

Beyond early detection, GPs play a multi-faceted role in all aspects of a patient's experience with cancer. For the most part, the GP's role in relation to cancer care also focuses on referral scheduling, patient advocacy, rehabilitation, dealing with patient symptoms, detection of recurrence, psychosocial support for patients and their families, treating co-morbidities related to cancers and palliative care survivorship (Klabunde et al, 2009; Hanks et al, 2008; McAvoy, 2007). Research highlights that when possible, GPs also play a key role in cancer prevention; particularly in relation to health promotion and education on lifestyle choices and behavioural changes in clinical practice (McAvoy, 2007).

Familial risk of cancer

For many types of cancer, a family history can increase an individual's risk. However, this is not due solely to inherited factors and can also be due to shared environmental/lifestyle risk factors within the family. Up to 5-10% of cancers are believed to be associated with an inherited susceptibility. Such cancer predisposition genes are typically involved in DNA repair mechanisms. The most well-known are the BRCA 1&2 genes, which are associated with an increased risk of breast and ovarian cancer predominantly. Features of cancers associated with heritability include cancers diagnosed at an unusually young age, multiple cancers in the same individual (e.g. breast and ovarian cancer or bilateral breast cancer) and unusual cancer types or specific histological subtypes.

Testing for a cancer predisposition gene generally starts with an individual who has been diagnosed with cancer and where there is a suspicion of a hereditary component. This is a test for inherited mutations, carried out on germline DNA from a blood sample, as opposed to other types of genetic testing which can be carried out on tumour cells. If a mutation is identified, this can be searched for in well family members. Management options for those found to carry a cancer predisposition gene include surveillance (e.g. regular colonoscopy for those with HNPCC/Lynch syndrome), prophylactic surgery (e.g. bilateral salpingo-oophorectomy in BRCA carriers) and chemoprevention (e.g. tamoxifen). This is a rapidly developing area, with improving technology and greater identification of inherited mutations which increase an individual's cancer risk.

Cancer survivorship

Cancer survivorship relates to patients who have finished their 'active' phase of cancer treatment, patients who continue to have treatment to manage side-effects, pre-existing comorbidities and/or chronic diseases related to their cancer diagnosis, and to patients who have their health monitored as part of a follow-up care programme to reduce risk of recurrence (Hoekstra et al, 2014). Cancer survivors may experience a wide range of complex health issues as a result of their cancer type and treatment. Some health issues can have a lifelong impact on patients, while others related to cancer treatment can last up to five years post-treatment (Heins et al, 2013). Research has shown that the quality of life of cancer survivors decreases (Geelen et al, 2014; Weaver et al, 2012). For up to five years post treatment, cancer survivors have increased rates of health care utilisation compared to non-cancer patients (Heins et al, 2013; Khan et al, 2011).

During active cancer treatment in secondary care settings, GPs may also provide care to their patients. One Netherlands based study, which focused on the role of GPs during active breast cancer treatment, found that GPs were heavily involved in overseeing treatment for side effects including nausea, pain and sleep disturbances, in psychological support and in the administration of endocrine therapy (Roorda et al, 2012). Post cancer treatment in secondary care settings, patients routinely participate in follow-up care with their GPs. In some instances, the transition back into the primary care setting can be difficult for both GPs and patients to navigate. Insufficient detail in medical notes and discharge letters from hospital consultants can be problematic for GPs to address the healthcare and psychosocial support needs of their patients (Guassora et al, 2015; Farquhar et al, 2005; Kousgaard et al, 2003). Yet, cancer survivors visit their GP more often than other patients (Hoekstra et al, 2014; Christensen et al, 2012; Heins et al, 2012; Nord et al, 2005).

Co-morbidity

Cancer, and certain cancer treatments, can increase the severity of certain co-morbid diseases including obesity, diabetes, osteoporosis, hyperthyroidism and early menopause (Heins et al, 2013; Ogle et al, 2000). A study by the Department of Health and Children found that approximately 30% of patients with cancer also experience depression (DOHC, 2008). Research suggests that cancer patients with comorbidities can have lower survival rates than those without comorbidity, dependent on site of cancer (Land et al, 2012; Iversen et al, 2009; Read et al, 2004). Comorbidity may also be associated with later detection of cancer and increased difficulty in treating cancer.

The National Cancer Control Programme

The National Cancer Control Programme (NCCP) was established in 2007 to implement the recommendations of the 2nd National Cancer Forum's report 'A Strategy for Cancer Control in Ireland 2006'. At the time, in 2006, the delivery of cancer services in Ireland was described as fragmented and not following best practice. The decision was made to centralise cancer care to eight designated cancer centres. In 2007, the ICGP published the findings of its study 'Barriers to Early Diagnosis of Cancer in Primary Care: A Needs Assessment of GPs' (Daly and Collins, 2007). The Community Oncology Programme of the NCCP was established in 2008. The key objectives were directly informed by the findings of the study.

One of the key aims of the NCCP is early referral of patients who present with signs and/or symptoms suggestive of cancer. The need for clear recommendations on the investigation and referral of patients presenting to their GP with possible signs of cancer has been well recognised. The NCCP, in association with the Irish College of General Practitioners and hospital based cancer specialists, has, to date, developed GP referral guidelines for suspected breast (2009), lung (2010) and prostate (2011) cancers and melanoma (2011); head and neck cancer referral advice for primary care was published in 2015; a GP referral guideline for suspected ovarian cancer is currently being piloted. These guidelines take account of existing published evidence-based referral guidelines and are applicable to the Irish healthcare setting and service configuration.

To facilitate the National GP Referral Guidelines, rapid access clinics for breast, lung, prostate and melanoma have been established. A standardised referral form was also developed in tandem with each guideline. The forms were designed to actively seek the information required for triage, plus other information of relevance if patients were to undergo certain investigations on the day of clinic attendance. Referrals are currently available as an online referral form (Healthlink Online) from the GP directly to the cancer teams. The GP receives immediate acknowledgement of receipt of referral from the cancer centre and also receives a clinical response from the cancer team within five working days.

Yet for all other forms of cancer, GPs must lean on their own experience and if relevant, guidelines such as the UK based *National Institute for Health and Care Excellence* (NICE) referral guidelines. Lack of access to a 'fast track system' at local hospitals for all other cancers and referral delays can be both challenging and concerning for GPs and their patients.

In recent months, the NICE have published the '*Suspected cancer: recognition and referral guideline*' (2015), which estimates that 5,000 lives could be saved in the UK annually if cancers are detected and diagnosed sooner. With a focus on symptom

based diagnosis rather than type of cancer diagnosis, the aim of the guideline is to improve early detection of cancers across all patient groups. Using a three tiered approach, the guideline organises recommendations into 'by site', 'by symptom' and 'by patient support'. The guideline has set an explicit threshold of risk in adults of 3%. The guideline also recommends timeframes of between 48 hours to two weeks for diagnostic tests. However, the impact of the guidelines on GP workloads and access to referral pathways is not yet known.

Methodology

Aims and objectives

The aim of this survey was to obtain the views and experiences of Irish general practitioners in relation to the work of the National Cancer Care Programme (NCCP) over the past seven years and to gain their opinions in relation to the future priorities of the NCCP which would assist GPs in their work.

Specifically, the objectives of this study were:

- To gauge GPs' views on the work of the NCCP to date in so far as it supports GPs.
- To gain insight on the current barriers encountered by GPs and their patients with suspected or confirmed cancer.

Study design

A project advisory group was convened to oversee the research between the ICGP and the NCCP. The group consisted of two members of the ICGP research team, one assistant national director and one GP with community oncology from the NCCP, one researcher from the Irish Cancer Society and one patient advocate.

A questionnaire was designed based on the original ICGP/Irish Cancer Society 'Early detection of cancer: a needs assessment of general practitioners' study carried out in 2006 and published in 2007. Questions were revised in view of the literature and developments since the commencement of the implementation of the National Cancer Strategy.

Postal questionnaires were sent in April 2015 to 2,822 ICGP members in the Republic of Ireland, excluding retired GPs and Trainees. Included with the questionnaire was an information sheet which informed potential participants of the details of the study including the purpose, process and data collection procedures. Return freepost envelopes were included to encourage response. 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 24 questions in four sections. GP and practice demographics were collected in Section 1, including number of years in general practice, total number of doctors in practice and distance of practice from nearest hospital and nearest designated cancer centre. Questions 2–7 sought GPs' views on the work of the NCCP to date and whether it supports GPs regarding the referral of patients with suspected breast, lung and prostate cancers and malignant melanoma. Questions 8–12 asked for GPs' experiences accessing services for patients with all forms of suspected cancer other than breast, lung, prostate and malignant melanoma. It also sought insight on which cancer referral guidelines GPs would like to see developed next by the NCCP. Questions 13–17 related to the targeted assessment of 'high risk individuals' including those with a history of familial cancers. GPs were asked about the supports they require regarding cancer survivorship and further cancer care education in questions 18–24. The questionnaire ended with an open ended question seeking further comments.

Data analysis

A total of 514 completed surveys from individual GPs were included in the final analysis, a response rate of 18.2%. 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. The open-ended survey were analysed thematically.

Findings

Section 1: Demographics and Respondent Profiles

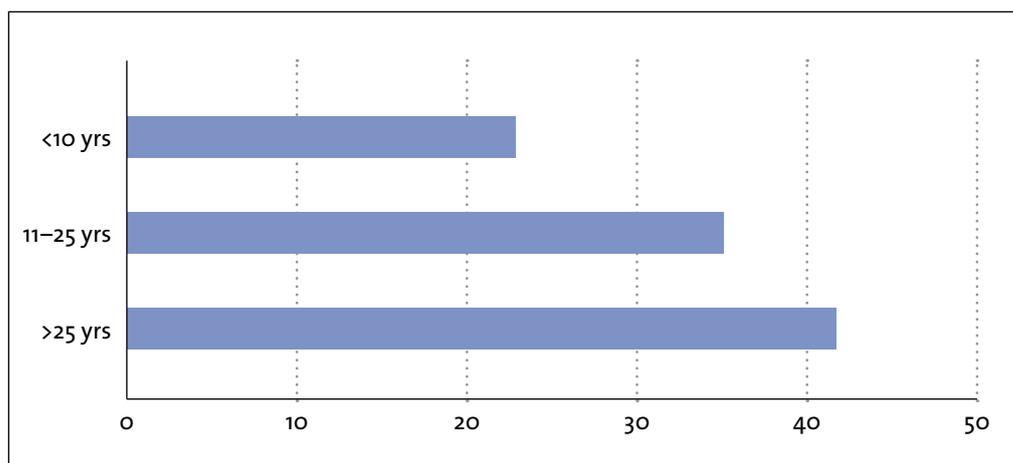
This section briefly sets out the demographics of the GPs who completed the survey in addition to providing some further geographical information.

A total of 514 completed surveys were included in the final dataset.

Of the respondents, 53.4% (n=270) were female and 46.6% (236) were male. This resembles ICGP membership statistics which show that 45% of the total population of GPs in practice in Ireland in 2015 are female.

Nearly 42% of respondents (n=210) were over 25 years in general practice, 35.3% (n=177) were between 11-25 years and 22.9% (n=115) were in practice 10 years or less. This corresponds with the original 'Early Detection of Cancer' survey (Daly and Collins, 2007), where the majority of respondents (74.6%) were experienced GPs with more than ten years in general practice.

Fig. 3 – Years in general practice (%)

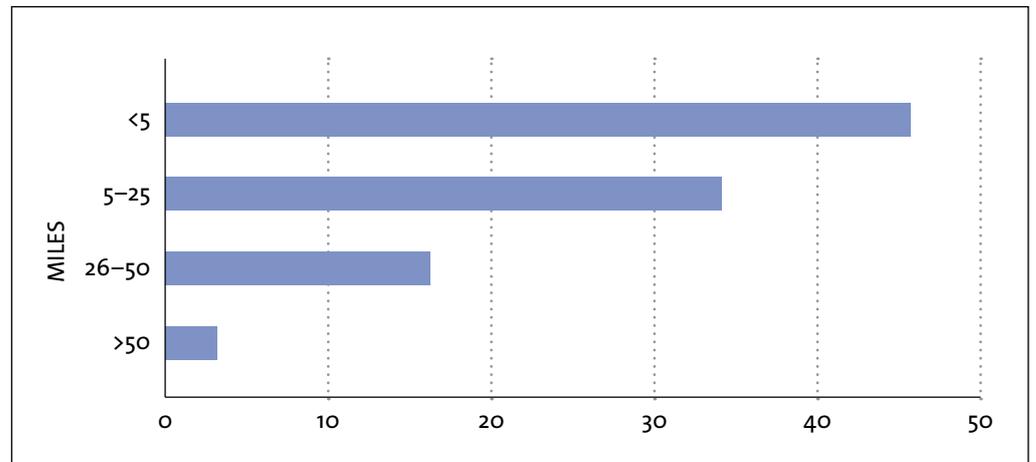


Overall, 36.4% of the respondents worked in single handed practices. Just over 85% (n=433) of GPs had a practice nurse in situ.

All counties in the Republic of Ireland were represented. The majority of practices were based in Dublin (26.6%, n=128), Cork (14.1%, n=70) and Galway (6.9%, n=34).

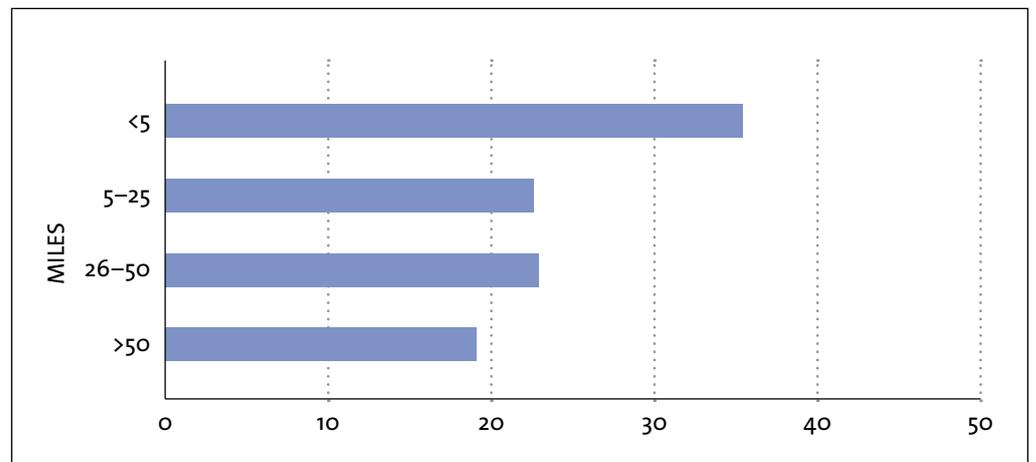
Overall, 45.8% (n=232) of practices were less than five miles from the nearest hospital to which a GP could refer a patient for assessment of suspected cancer. Just over 34% (n=173) were between 5-25 miles and 16.4% (n=83) were between 26-50 miles from the nearest suitable hospital. Small proportions (3.6%) of practices were over 50 miles from the nearest hospital.

Fig. 4 – Distance to nearest hospital for referral for assessment of suspected cancer (%)



Of those surveyed, 35.4% (n=176) of practices were less than 5 miles from the nearest designated cancer centre. Equal numbers 22.9% and 22.5%, were between 5-25 miles and 26-50 miles from the nearest centre. Approximately 19% (n=95) of practices were over 50 miles from the nearest cancer centre.

Fig. 5 – Distance to nearest designated cancer centre (%)

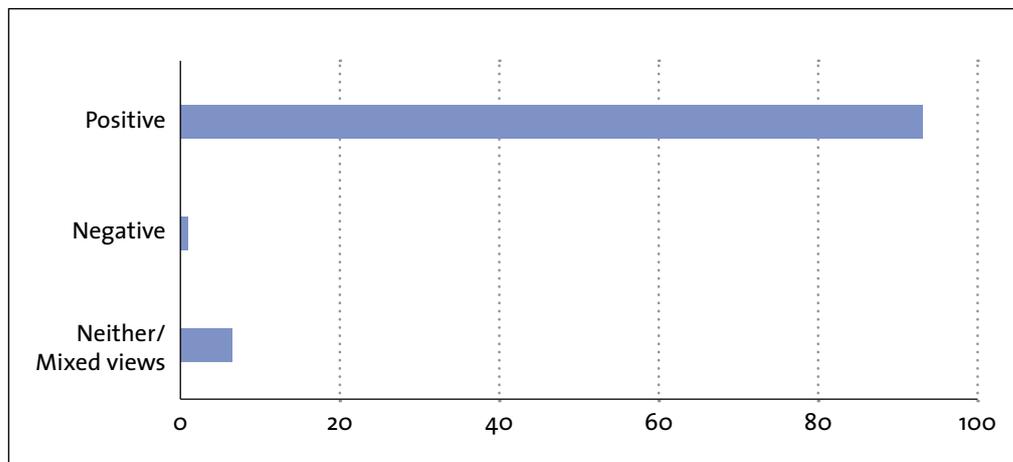


Overall, 22.6% (n=111) of GP practices were located within 25 miles of both a hospital to which they could refer patients and a designated cancer centre. Of those, one quarter were located within five miles or less of both.

Section 2: Referrals

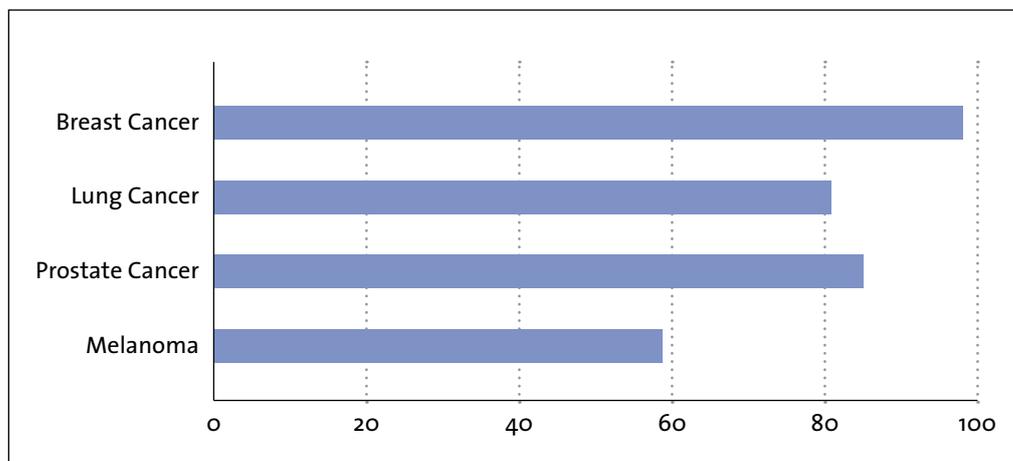
The vast majority (93.3%, n=476) of GPs considered the organisation of cancer services into designated cancer centres as a positive step, with only three respondents regarding this re-organisation negatively. A little over 6% were unsure or had mixed views on this point.

Fig. 6 – Views on the organisation of cancer services into designated cancer centres (%)



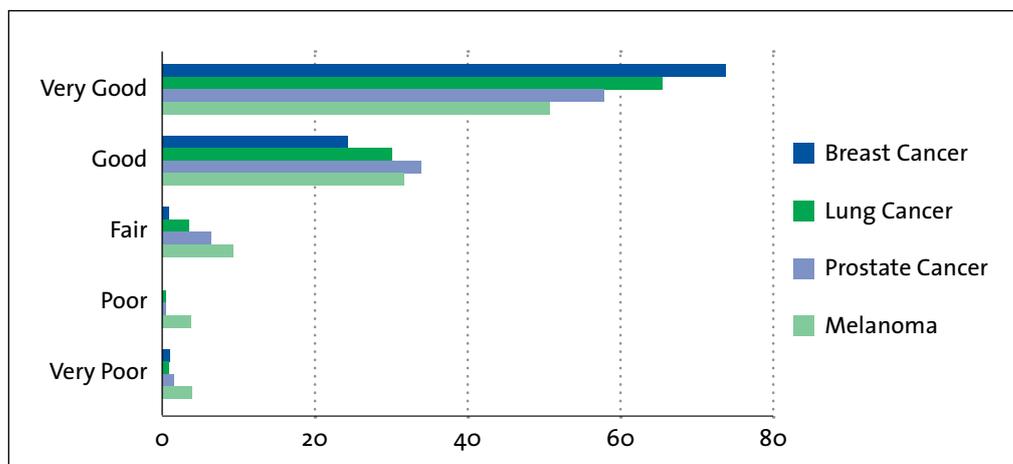
GPs were asked to indicate which of the four current NCCP National GP Referral Guidelines (breast, lung, prostate and melanoma) they were familiar with. An overwhelming majority of GPs (98.2%) were familiar with breast cancer guidelines; 85% familiar with prostate cancer, 80.9% with lung cancer and 58.5% with melanoma referral guidelines.

Fig. 7 – Familiarity with NCCP national GP referral guidelines (%)



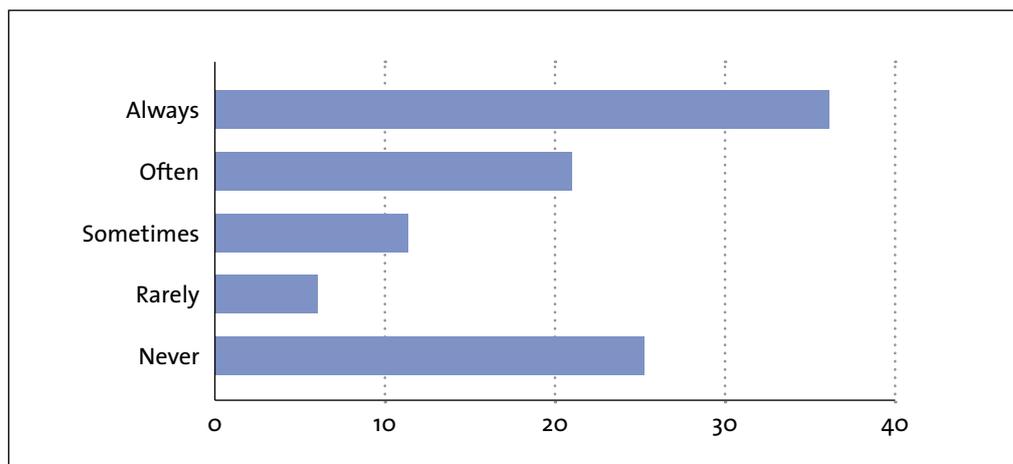
When asked to rate the current NCCP National GP Referral Guidelines in order of 'very good' to 'very poor', breast cancer (98.1%), lung cancer (95.5%) and prostate cancer (91.7%) were the most favourably rated. Approximately 82.5% of GPs indicated a 'good' to 'very good' rating for the malignant melanoma referral guidelines.

Fig. 8 – GPs rating of the NCCP National GP Referral Guidelines (%)



Overall, 57.1% (n=291) of GPs reported that they ‘always’ or ‘often’ used electronic referral, while 31.4% (n=160) indicated that they ‘never’ or ‘rarely’ used it and 11.4% (n=58) of GPs ‘sometimes’ used it.

Fig. 9 – Use of electronic referral (%)

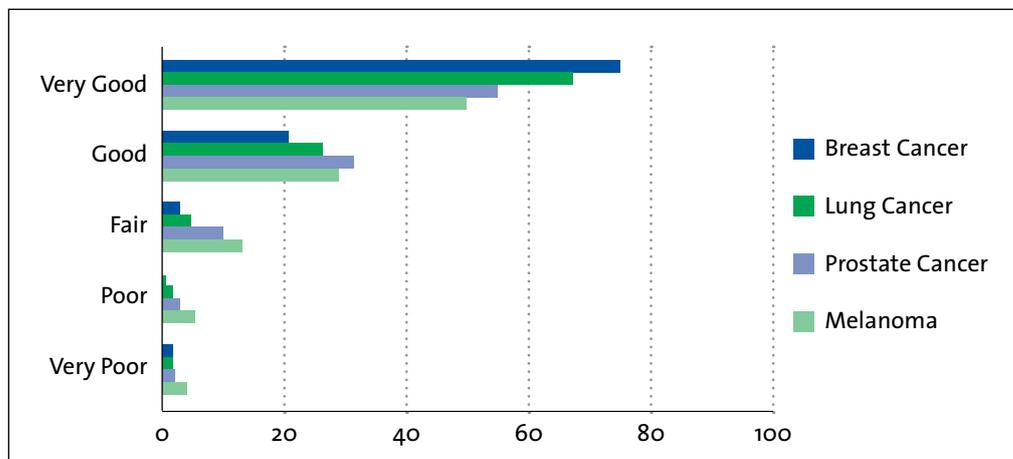


GPs who ‘never’ or ‘rarely’ used electronic referral were given the opportunity to expand on this via an open-ended response. Of the 102 GPs who provided further detail, the most common themes were; ‘technological/access issues’ (n=38), ‘convenient to write paper version and fax/post’ (n=26), ‘don’t know how’ (n=14), ‘unaware of electronic version’ (n=7), ‘assumption that the form was for breast only’ (n=2).

Just over 57% (n=279) of GPs reported that they were aware of the NCCP website, however 71.1% (n=329) indicated that they had never used it.

GPs were asked to rate their experience to date with rapid access clinics when referring patients with suspected breast, lung, prostate and melanoma cancers. The majority (95.5%) of GPs indicated that they had a ‘very good’ or ‘good’ experience when referring patients with suspected breast cancer; nearly 94% of GPs had a positive experience for suspected lung cancer and 85.8% for prostate cancer. Just over 78% reported a positive experience for suspected melanoma.

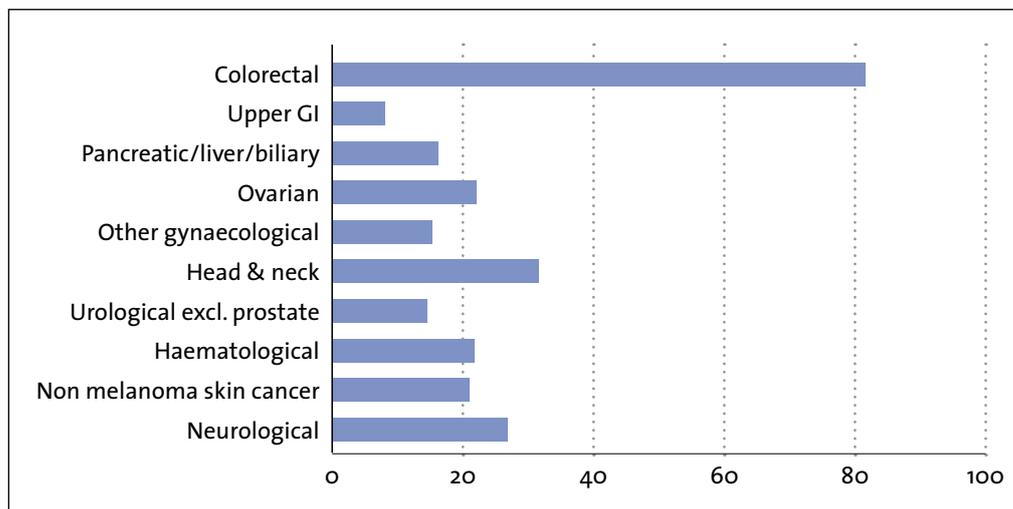
Figure 10 – Experience to date with Rapid Access Clinics (%)



Section 3: Other cancers

When asked to indicate what other cancer referral guidelines they would like to see developed, just over 81% of GPs (n=340) selected colorectal as their top preference. Following this, in order of number one preference 31.6% selected head and neck, 26.7% selected neurological, 22% selected ovarian, 21.7% selected haematological and 21.1% non-melanoma skin cancer. Only 7.8% indicated upper GI as their top preference for guidelines.

Fig. 11 – Cancer referral guidelines GPs would like to see developed: first choice (%)

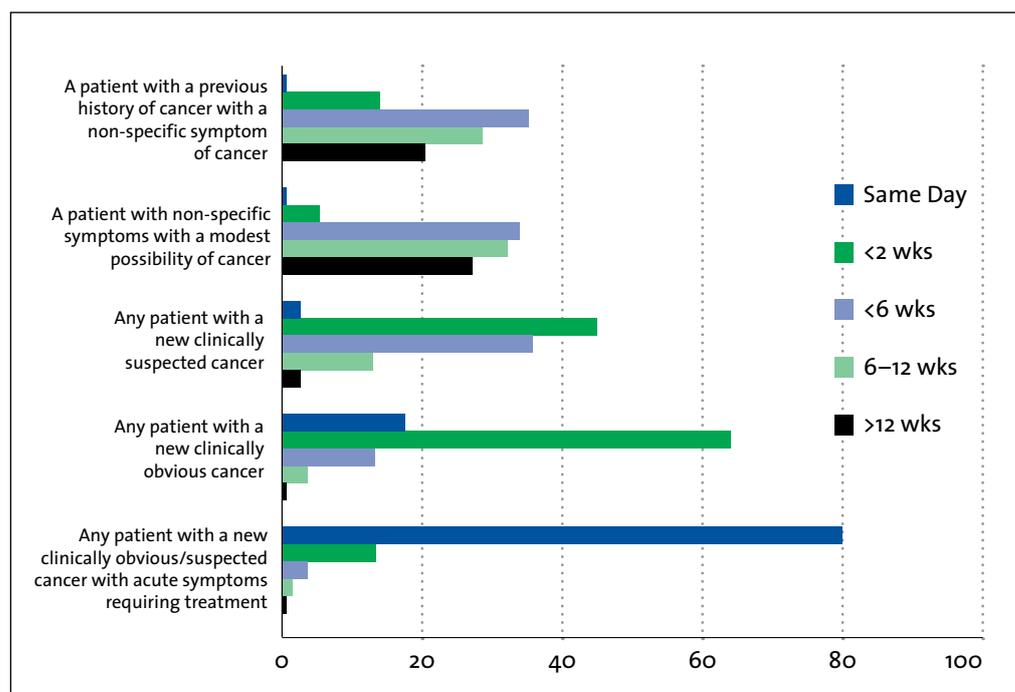


GPs were given six options and asked to indicate for each whether or not they consider patients with various signs and symptoms to be ‘urgent’. The majority in each category notably considered the first three patient categories to be urgent (Table 1). However, just over one fifth (n=108) considered ‘a patient with a previous history of cancer with a non-specific symptom of cancer’ to be ‘urgent’; and 14.6% (n=75) regarded ‘a patient with non-specific symptoms with a modest possibility of cancer’ as ‘urgent’. These findings are exactly comparable in order of ranking as those from the 2007 study.

Table 1 – Patients GPs consider to be urgent

EXPERIENCE TO DATE WITH RAPID ACCESS CLINICS	N	%
Any patient with new obvious/suspected cancer with acute symptoms requiring treatment	444	86.4
Any patient with a new clinically obvious cancer	381	74.1
Any patient with a new clinically suspected cancer	286	55.6
A patient with a previous history of cancer with a non-specific symptom of cancer	108	21.0
A patient with non-specific symptoms with a modest possibility of cancer	75	14.6

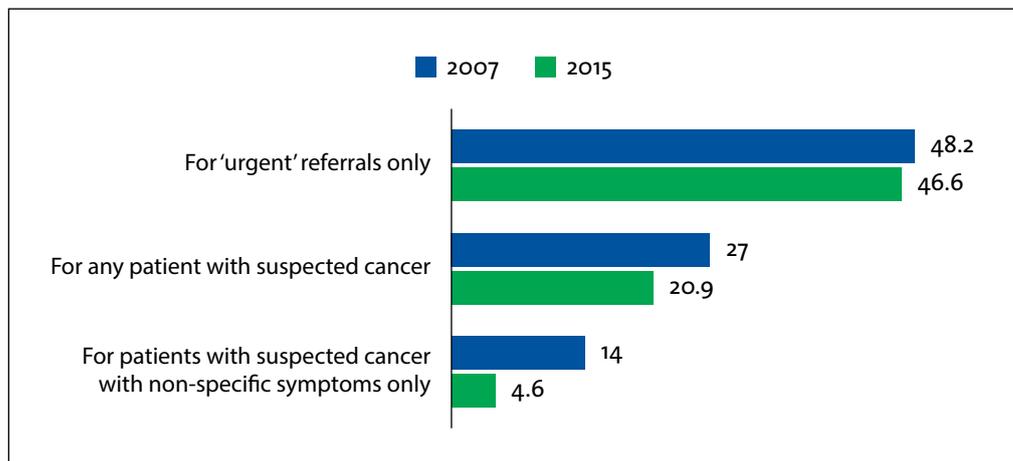
The majority of GPs (80.7%) reported that urgent patients with acute symptoms requiring treatment were seen on the ‘same day’ as referral. This is a dramatic increase on 2007 figures which identified that only one-third of urgent patients received an appointment on the same day as referral. Any patient with a new clinically obvious cancer most commonly had a waiting period of between one day and two weeks (64.3%); 84% of patients with a new clinically suspected cancer were waiting six weeks for assessment. Nearly 60% of patients with non-specific symptoms with a modest possibility of cancer had a waiting time of six weeks or more; while nearly 50% of patients with a previous history of cancer with a non-specific symptom of cancer were waiting six weeks or over.

Fig. 12 – Patient waiting times for initial hospital assessment (%)

Nearly 47% (n=221) of GPs had access to a fast track system (e.g. rapid access clinic) for ‘urgent’ referrals. Just over one fifth had such access for any patient with suspected cancer. These figures are similar to the 2007 study where 48.2% had access to a fast

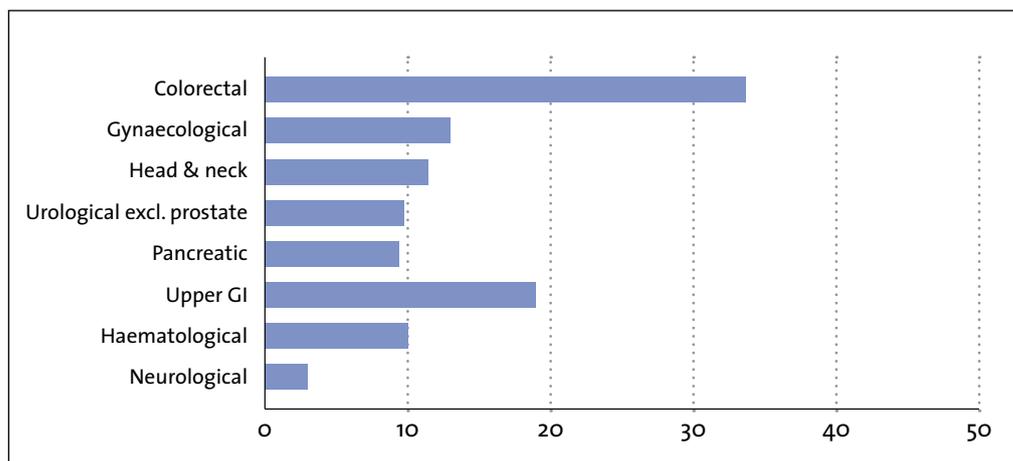
track system for urgent referrals and 27% for patients with suspected cancer. In the most recent survey, only 4.6% had access for patients with suspected cancer with non-specific symptoms only, an absolute figure of 10% less than in 2007.

Fig. 13 – Access to a ‘fast track system’ at local hospital for ‘other’ suspected cancers (%)



GPs indicated whether they had access to a fast track system for patients with symptoms or signs of a specific cancer (Figure 14). This access was most commonly available for colorectal (33.7%), upper GI (19.1%), gynaecological (13%) and head and neck (11.5%). Access was limited for haematological (9.9%) and neurological (3.1%) cancers.

Fig. 14 – Cancers for which a ‘fast track system’ is available (%)



Of the 31 GPs who specified ‘other’, the most common responses were; ‘no official fast track systems’ (n=12), ‘availability confirmed by contacting consultant’ (n=8), ‘dermatological’ (n=6) and ‘breast/lung/prostate only’ (n=3).

A directory of services at their local hospital for patients with suspected cancer is only available for slightly less than one third (30.2%) of GPs with regard to investigation and to approximately 37% of GPs with regard to referral (Table 2).

Nearly half (49.7%) of GPs had sufficient information regarding required modes of communication for investigation, while 52.4% had enough information for referral.

Nearly 60% of GPs reported that they *did not have* key contact details at their local hospital(s) with regards to investigation for a patient with suspected cancer. Similarly just over 56% indicated that they didn't have key contact details for referral.

Just over 69% of GPs reported having delayed investigation and 64.8% having delayed referral of patients with suspected cancer due to difficulty in accessing services.

Over four fifths of GPs reported having sent patients to emergency departments to bypass such difficulties in accessing services.

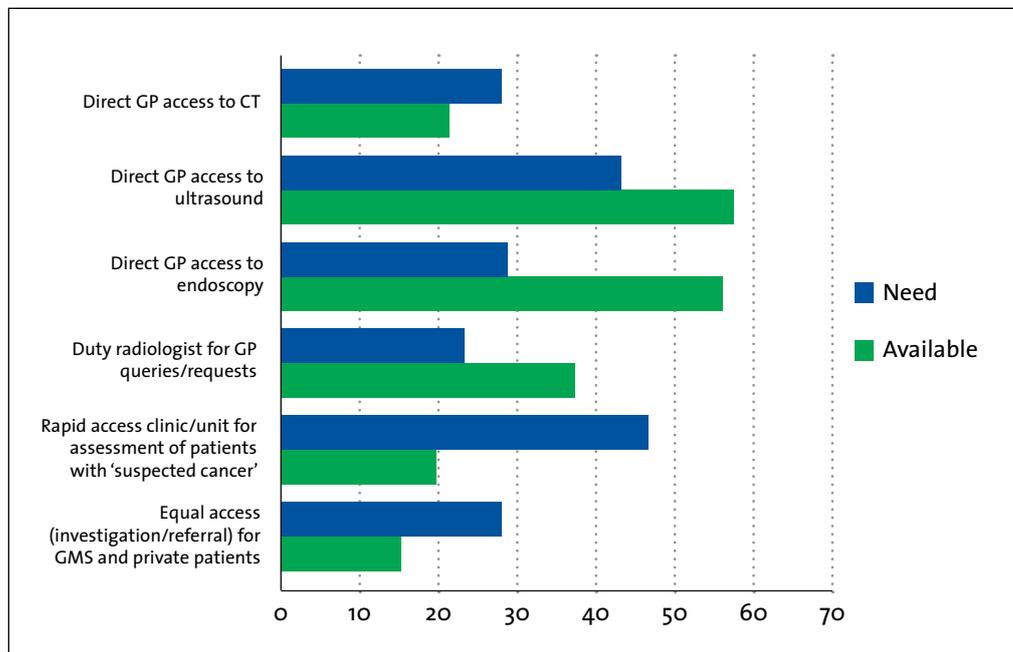
Table 2 - Investigation or referral to local hospitals of patients with suspected cancer

	INVESTIGATION		REFERRAL	
	Yes	No	Yes	No
Have a directory of services?	141 (30.2%)	326 (69.8%)	155 (36.7%)	267 (63.3%)
Have sufficient information on required mode of communication e.g. form/letter/fax/phone/electronic?	230 (49.7%)	233 (50.3%)	225 (52.4%)	204 (47.6%)
Have key contact details?	184 (40.1%)	275 (59.9%)	187 (43.9%)	239 (56.1%)
Ever delay because of difficulty in accessing services?	315 (69.1%)	141 (30.9%)	271 (64.8%)	147 (35.2%)
Send patients to A&E to bypass difficulty in accessing services?	398 (85.6%)	67 (14.4%)	357 (83.2%)	72 (16.8%)

GPs were asked to identify which six factors (Figure 15) were 'available' at their local hospital(s) to increase early detection/diagnosis of cancers. The most frequently selected were 'direct GP access to ultrasound' (57.6%), 'direct GP access to endoscopy' (56.2%) and 'duty radiologist for GP queries/requests' (37.4%). The least available factor was 'equal access (investigation/referral) for GMS and private patients' (15.2%).

With the same six factors, GPs were asked to select the most important factor in their opinion, which they do not have, but need, at their local hospital(s). The most commonly selected were 'rapid access clinic/unit for assessment of patients with suspected cancer' (46.8%) and 'direct GP access to ultrasound' (43.2%). The original 2007 study reported that 'rapid access clinic/unit' factor was also the most frequently selected factor (45.6%).

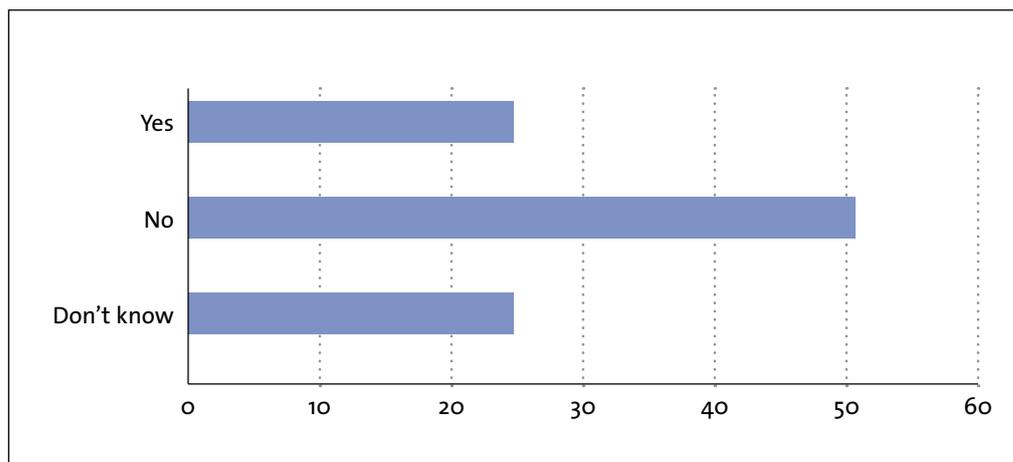
Fig. 15 – Most important factor identified by GPs for patients at local hospital(s) to increase early detection/diagnosis of cancers (%)



Section 4: Targeted assessment of 'high risk individuals'

A little more than half of GPs (50.7%) considered that they did not have the information they need to assess patients with regard to their individual risk of cancer. Equal numbers of GPs reported having sufficient information (24.6%), or unsure if they had or not (24.6%).

Fig. 16 – Access to information required to assess patients with regard to their individual risk of cancer (%)

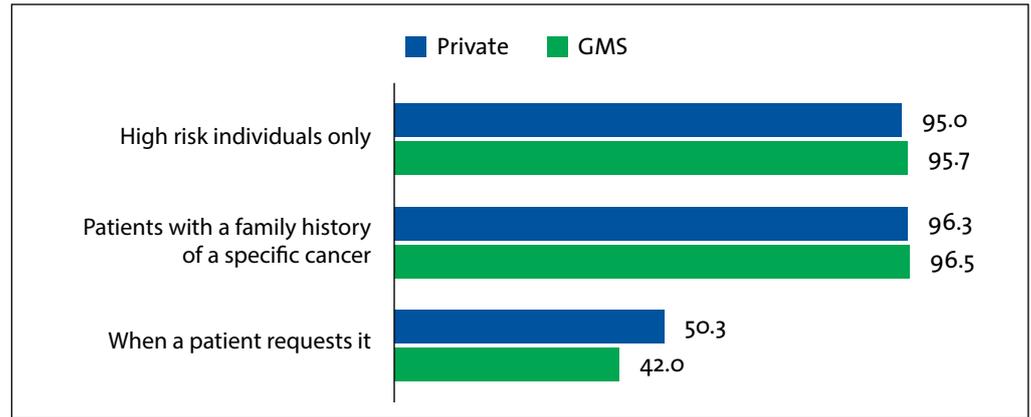


The majority of GPs (93.7%) reported that they would like the NCCP to develop guidelines on risk assessment in relation to a family history of cancer.

Similar to the 2007 findings, GPs scheduling additional/targeted assessment tests for patients did not vary according to their patients GMS or private status (Figure

17). In the vast majority of cases, GPs would recommend additional or targeted assessment tests for 'high risk individuals only' and likewise for patients with a family history of cancer. If a patient requests additional investigation, just over half of GPs would recommend it in the private setting, while 42% of GPs would recommend additional investigation for GMS patients.

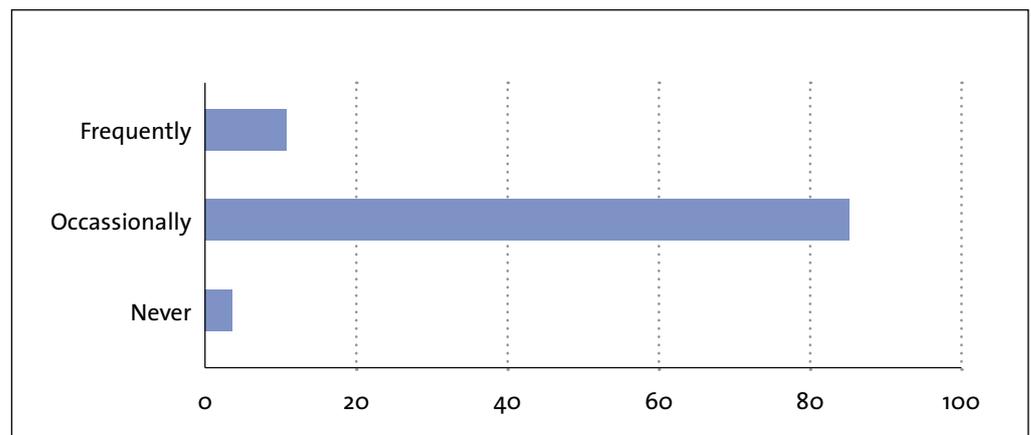
Fig. 17 – Circumstances in which a GP would recommend additional/targeted assessment tests (%)



Of the 14 GPs who selected 'other' and provided insight in relation to the circumstances in which they would recommend targeted assessment tests, all stated that they would make the decision based on their knowledge of each patient's medical history.

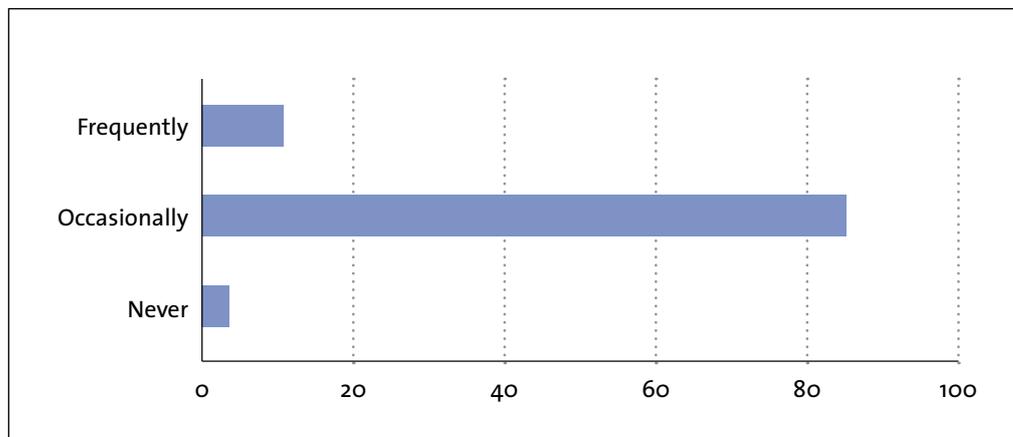
Approximately four out of five GPs (n=357, 81.5%) reported that patients with a family history of potentially hereditary cancers (e.g. breast, ovary, colorectal) request genetic testing; a decrease of 14% compared to the 2007 study.

Fig. 18 – Genetic testing requests (%)



In relation to GPs who responded yes to the above (n=357), 85.4% indicated that their patients 'occasionally' requested genetic testing. There was a substantial drop in the percentage of patients who 'frequently' request testing, from 68% in 2007 to 11% in 2015.

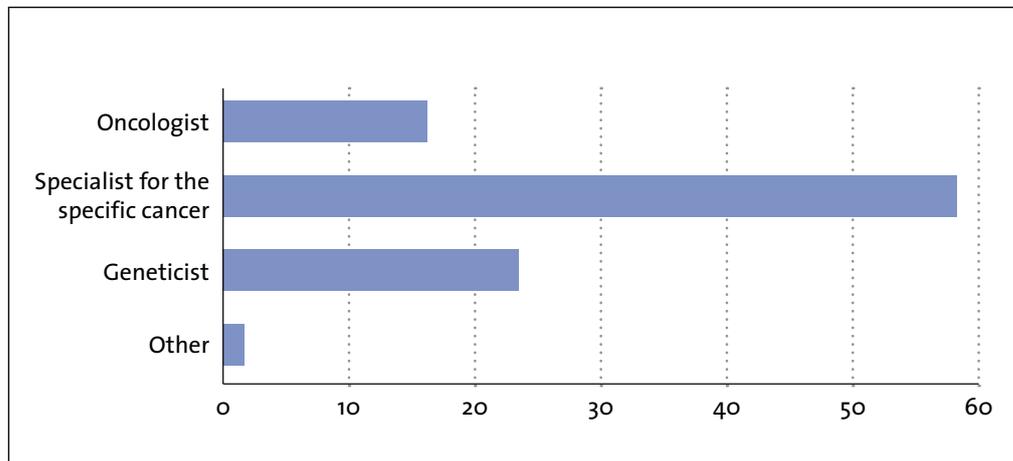
Fig. 19 – Frequency of genetic testing requests (%)



Approximately 90% (n=429) of GPs reported that they did not have sufficient information to discuss genetic testing with patients. Nearly 55% (n=263) of GPs considered that they have sufficient information to discuss modifiable risk factors with these patients.

With regard to formal risk assessment/consideration for genetic testing, over half (58.7%, n=288) of GPs referred patients to a specialist for the specific cancer, nearly 24% (n=116) referred to a geneticist and 16% (n=79) referred to an oncologist. Overall, these figures are similar to those from the 2007 study.

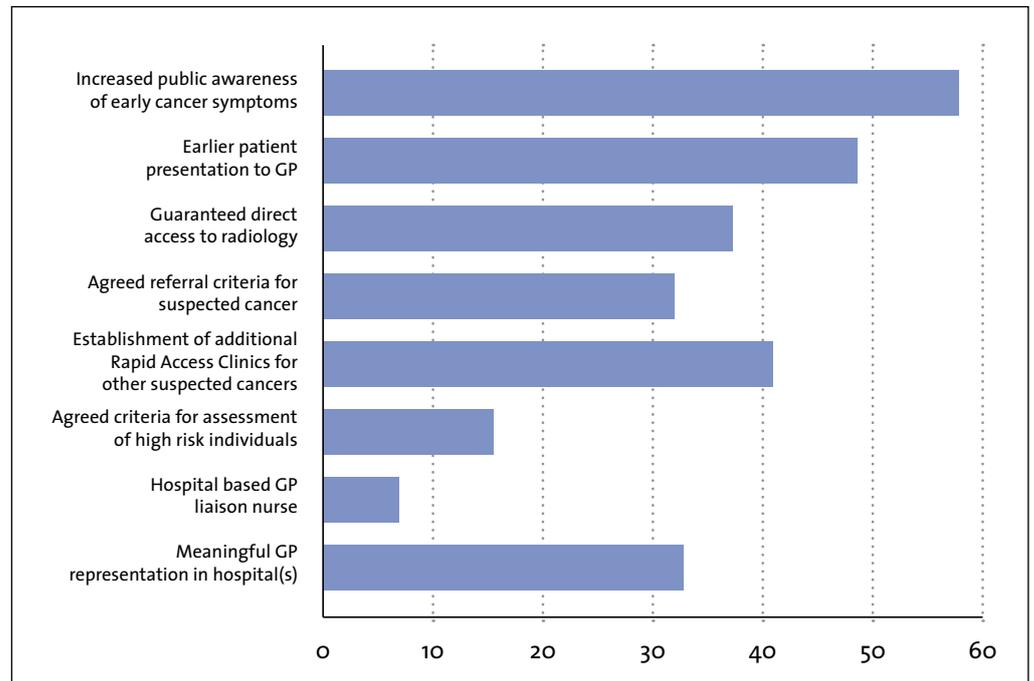
Fig. 20 – Formal risk assessment/consideration for genetic testing: to whom are patients referred (%)



Of those GPs who offered insight (n=28) on ‘other’ referrals they make for formal risk assessment, the most common responses were; ‘varies on access/availability’ (n=8), ‘all three of the above’ (n=3), ‘don’t know’ (n=3) and ‘nurse specialist’ (n=1).

When asked to identify which of eight factors (Figure 21) would assist GPs most in the early detection of cancer in their practice, increased public awareness of early cancer symptoms rated highest at 57.9%. Just fewer than 49% selected earlier patient presentation to GP, while over 41% selected the establishment of additional rapid access clinics for other suspected cancers. The least commonly selected factor was hospital based GP liaison nurse (7.2%) and agreed criteria for assessment of high risk individuals (15.8%).

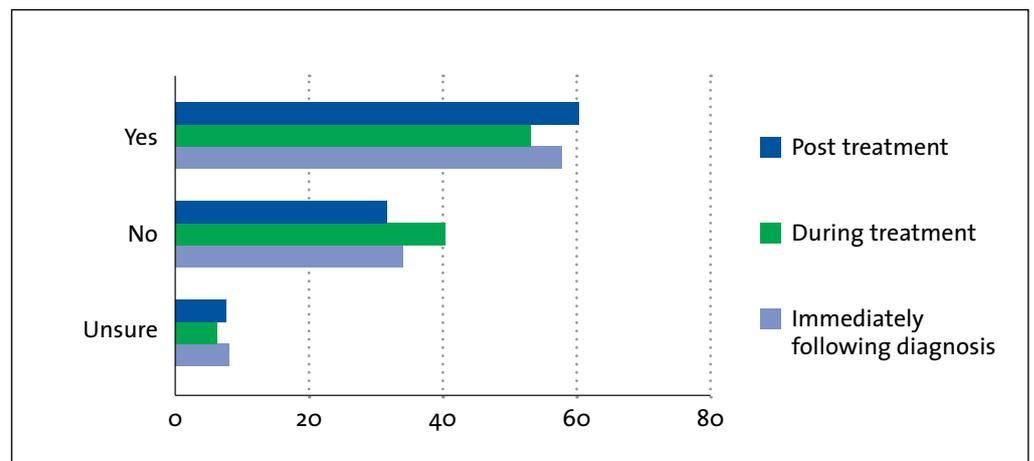
Fig. 21 – Factors which would assist in the early detection of cancer in GP practices (%)



Section 5: Cancer survivorship

Just over six out of ten (60.5%) GPs reported that they are receiving enough information from their ‘hospital’ or consultant about their patients ‘post treatment’ with 58% of GPs receiving information ‘immediately’ following a cancer diagnosis, while slightly more than half (53.4%) received information ‘during treatment’.

Fig. 22 – Receiving enough information from hospital/consultant about patients who have received a cancer diagnosis (%)

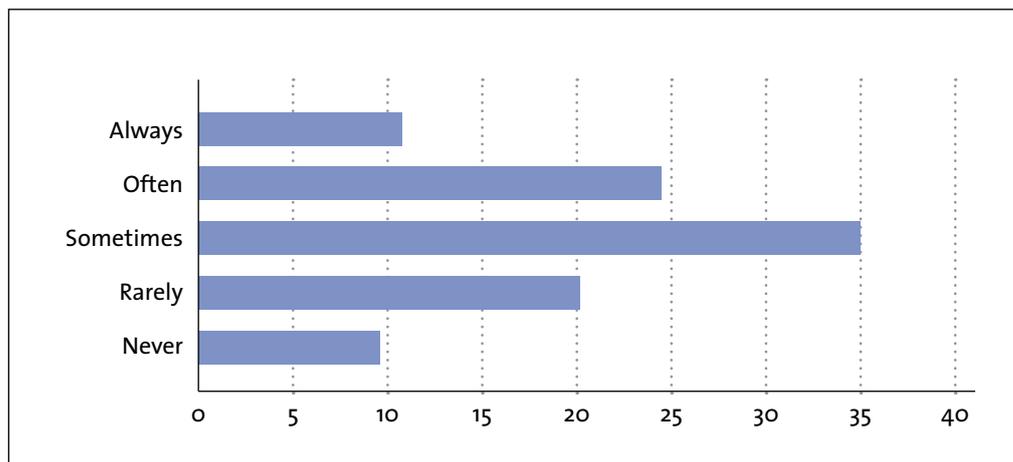


A large portion of GPs (93.5%) had never attended a survivorship course, conference or workshop.

Nearly 60% of GPs indicated that they would like to receive further education in the area of cancer survivorship.

With regard to GPs sharing follow-up care for their patients with oncology consultants, 10.7% reported this occurs always, 24.5% often and 35% sometimes. Just over 20% report they 'rarely' share follow-up care and approximately 9.7% had 'never' experienced sharing follow-up care.

Fig. 23 – Sharing follow-up care for patients with oncology consultants (%)



In all but one area, 'smoking cessation services', GPs reported that services were more widely available to their private patients than GMS patients (Table 3).

Approximately two-thirds of GPs reported that 'cancer rehabilitation programmes' were not available to their GMS (66.5%) or private patients (60%).

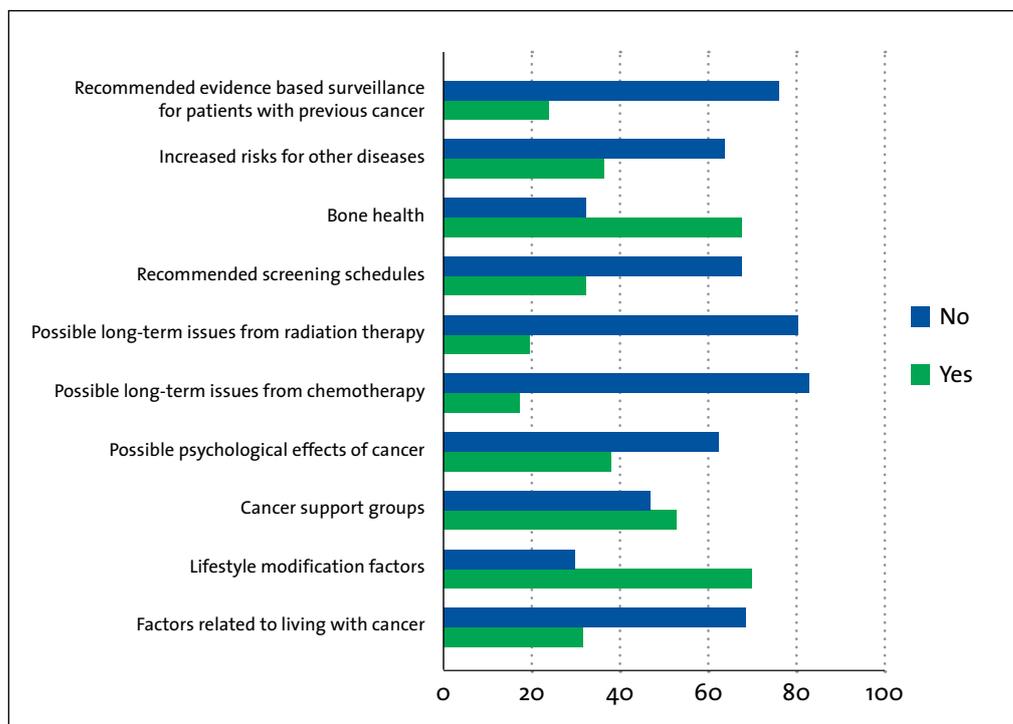
Only 17% of GPs indicated that 'fertility counselling and resources' were available to GMS patients, while 40% of private patients had access to such services. Similar discrepancies were noted for 'sexual counselling and resources' and 'family counselling and resources'.

Table 3 – GPs views on whether services are readily access to their patients:

	GMS		PRIVATE	
	Yes	No	Yes	No
Cancer rehabilitation programmes	163 (33.5%)	323 (66.5%)	181 (40.0%)	272 (60.0%)
Pain and symptom management programmes	234 (47.4%)	260 (52.6%)	296 (63.7%)	169 (36.3%)
Bone health educational programmes (e.g. osteoporosis)	137 (28.1%)	351 (71.9%)	190 (41.5%)	268 (58.5%)
Psychosocial support / Psycho-oncology services	193 (39.9%)	291 (60.1%)	224 (49.0%)	233 (51.0%)
Family counselling and resources	144 (30.5%)	328 (69.5%)	184 (41.4%)	260 (58.6%)
Fertility counselling and resources	79 (17.0%)	385 (83.0%)	176 (40.0%)	264 (60.0%)
Sexual counselling and resources	44 (9.5%)	420 (90.5%)	104 (23.7%)	334 (76.3%)
Genetic cancer counselling	102 (21.9%)	364 (78.1%)	178 (40.3%)	264 (59.7%)
Smoking cessation services	365 (75.3%)	120 (24.7%)	345 (75.7%)	111 (24.3%)
Dietician	234 (48.2%)	251 (51.8%)	319 (69.5%)	140 (30.5%)

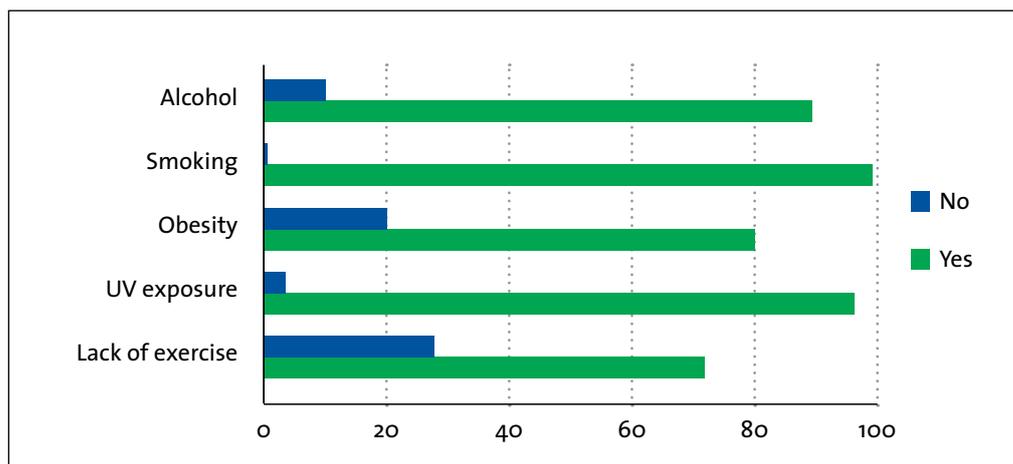
In all but three 'cancer' related areas, GPs indicated that they did not have enough information to provide care to their patients (Figure 24). Those three areas were 'lifestyle modification factors' (70.1%), 'bone health' (67.6%) and 'cancer support groups' (53%). Only 17.2% and 19.7% of GPs respectively considered that they had enough information on the 'possible long-term issues from chemotherapy' and 'possible long-term issues from radiation therapy'. Just over 76% of GPs considered that they did not have sufficient information on 'recommended evidence based surveillance for patients with a previous cancer'.

Fig. 24 – GP access to relevant information to provide patient care (%)



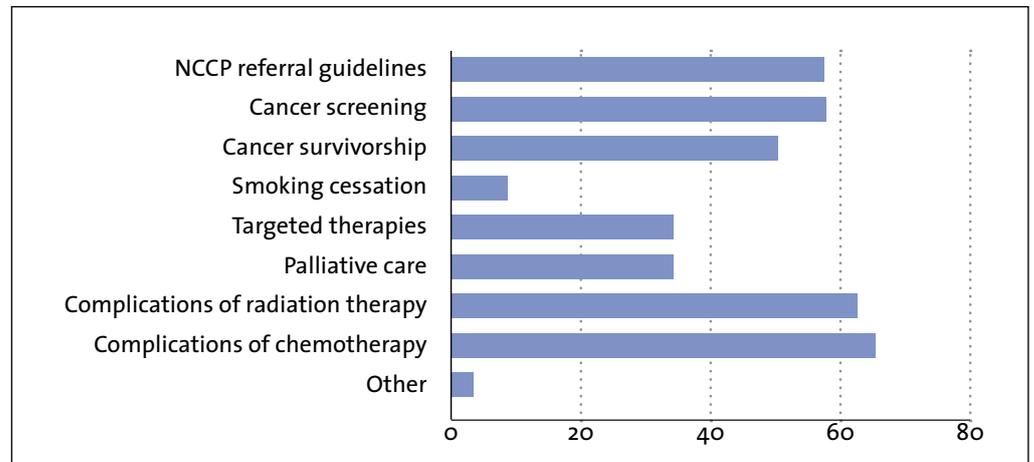
Nearly all of the GPs surveyed highlighted to their patients the increased risk of cancer related to ‘smoking’ (99.2%) and ‘UV exposure’ (96%). The majority of GPs also highlighted the risks related to ‘alcohol’, ‘obesity’ and ‘lack of exercise’.

Fig. 25 – Percentage of GPs who communicate to patients the increased risk of cancer (%)



When asked to select from a list, those areas of cancer in which they would like to receive further education, ‘complications of chemotherapy’ (65%), ‘complications of radiation therapy’ (62.3%), ‘cancer screening’ (57.4%) and ‘NCCP referral guidelines’ (57%) were the most commonly selected topic areas. ‘Smoking cessation’ ranked the lowest at 8.6%.

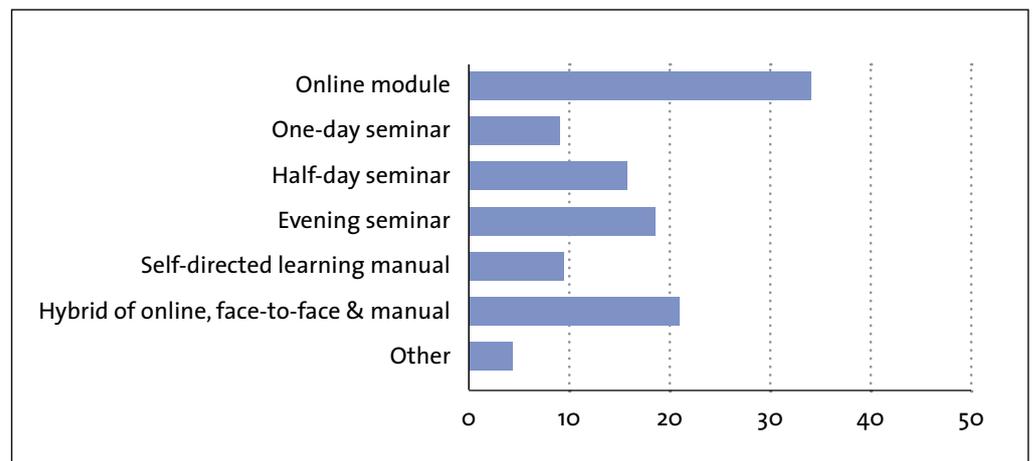
Fig. 26 – Areas in which GPs wish to receive further education (%)



Of the 16 GPs who provided additional information on ‘other’ areas in which they would like to receive further education, topic areas included ‘symptom management’, ‘counselling’, ‘evidence based surveillance of patients with a previous cancer’, ‘risk factors for families’ and ‘types of supports available and how to access them’. Three GPs identified that they were uninterested in receiving further information due to time restraints in general practice.

When asked to select their preferred format to receive additional cancer related education, ‘online module’, ‘hybrid of online, face to face and manual’ and ‘evening seminar’ were the most commonly selected formats (Figure 27).

Fig. 27 – Preferred further education format (%)



Twelve GPs suggested that the most appropriate format to receive additional cancer related education was via continuous medical education (CME) meetings.

Discussion and Recommendations

This survey provides some insight into the current situation with regard to cancer detection, investigation and treatment from a GP perspective. The results point to some key actions points for both the NCCP and ICGP but also for other stakeholders in the health care system in Ireland.

The majority of GPs who responded to this survey consider the organisation of cancer services into designated cancer centres as positive. Experience with referring patients to the rapid access clinics was very good and the NCCP referral guidelines were rated well. Familiarity was high with regard to NCCP referral guidelines for breast, lung and prostate cancers; however, some work is required to increase awareness of the melanoma referral guidelines. With almost one third of GPs not using the available electronic referral forms, some attention to the issues highlighted is required, which centre on technology/access issues and convenience. Referral guidelines for colorectal cancer and guidelines on risk assessment in relation to a family history of cancer would be welcomed by GPs. The inequity between GMS and non-GMS patients with regard to accessing services available to cancer survivors requires action.

For cancers where rapid access clinics are not currently available, less than half of GPs had a fast track system at their local hospital and movement towards the provision of such rapid access is a necessity across all cancers.

The lack of service information and hospital contact details is a regular complaint and development of such directories would surely facilitate GP-hospital communication and referral processes. In terms of specific services for cancer patients, GPs highlighted the need for rapid access clinics/units for the assessment of patients with suspected cancer and direct GP access to ultrasound.

For patients with a family history of cancer, GPs point to having insufficient information regarding genetic testing in particular but information on modifiable risk factors for these patients is also required. Further education related to cancer survivorship was requested by 60% of respondents, providing more information specifically on complications of chemotherapy and radiation therapy, cancer screening and NCCP Referral Guidelines.

Overall, the GPs who responded to this survey considered that increased public awareness of early cancer symptoms, earlier patient presentation and rapid access clinics were the three factors which would impact most on the early detection of cancer in Ireland.

Recommendations and Conclusion

In light of the findings, the following recommendations are proposed:

Guidelines

The NCCP should continue to develop and launch National Referral Guidelines for the most common cancers, and in particular as indicated by GPs in this study, colorectal cancer, neurological cancer and cancers of the head and neck. There is also a need for clinical practice guidelines in the area of cancer survivorship and risk assessment in relation to a family history of cancer.

Access to Diagnostics

Access to diagnostics is crucial for improved cancer outcomes. There is an urgent need for the Health Service Executive (HSE) to establish clear pathways for direct GP access to investigations and diagnostics.

Resources

Funding should be provided for continuing research into related topic areas, with a particular focus on cancer survivorship. Adequate funding should also be made available to educate GPs on subject areas they have prioritised including NCCP referral guidelines and cancer screening. In addition, GPs identify a need for accessible information on areas of cancer care including possible long-term issues from chemotherapy and radiotherapy and factors related to living with cancer.

Cancer Awareness Campaigns

Cancer awareness campaigns should be devised to support the early diagnosis of cancer. This includes educating the public on possible signs and symptoms and how to reduce cancer risk. They must also ensure that GPs are provided with information and education and are made aware of the resources available for their patients.

In summation, the key findings of this study are a need for:

- Increased patient awareness
- Elimination of inequity between public and private patients
- Improved community diagnostics
- More referral criteria for suspected cancers
- More rapid access clinics
- Improved communication with hospitals
- Further education and clinical practice guidelines on survivorship
- Education on complications of treatment

References

1. Allgar, V.L. and Neal, R.D. (2005) General practitioners' management of cancer in England: secondary analysis of data from the National Survey of NHS Patients-Cancer. *Eur J Cancer Care (Engl)* 14(5):409-16.
2. Banks, J., Hollinghurst, S., Rigwood, L. et al. (2014) Preferences for cancer investigation: a vignette-based study of primary-care attendees. *Lancet Oncol*, 15:232-40.
3. Cancer Research UK (2014) Saving lives, averting costs: An analysis of the financial implications of achieving earlier diagnosis of colorectal, lung and ovarian cancer. Available [here](#) (accessed 8 September 2015).
4. Christensen, K.G., Fenger-Grøn, M., Flarup, K.R. and Vedsted, P. (2012) Use of general practice, diagnostic investigations and hospital services before and after cancer diagnosis - a population-based nationwide registry study of 127,000 incident adult cancer patients. *BMC Health Serv Res*, 12:224.
5. Daly, H. and Collins, C. (2007) Barriers to Early Diagnosis of Cancer in Primary Care: A Needs Assessment of GPs. *Ir Med J*, 100(10):624-6.
6. Farquhar, M.C., Barclay, S.I.G., Earl, H., Grande, G.F., Emery, J. and Crawford, R.A.F. (2005) Barriers to effective communication across the primary / secondary interface: examples from the ovarian patient journey (a qualitative study). *European Journal of Cancer Care*, 14: 359-366.
7. Geelen, E., Krumeich, A., Schellevis, F.G. and Akker, M. van den. (2014) General practitioners' perceptions of their role in cancer follow-up care: a qualitative study in the Netherlands. *European Journal of General Practice*, 20(1), 17-24.
8. Guassora, A.D., Jarlbaek, L. and Thorsen, T. (2015) Preparing general practitioners to receive cancer patients following treatment in secondary care: a qualitative study. *BMC Health Services Research*, 15:202.
9. Hamilton, W. (2009) The CAPER studies: five case-control studies aimed at identifying and quantifying the risk of cancer in symptomatic primary care patients. *Br J Cancer*, 101(Suppl. 2):S80-6.
10. Hanks, H., Veitch, C. and Harris, M. (2008) Colorectal cancer management - the role of the GP. *Aust Fam Physician*, 37(4):259-61.
11. Heins, M., Schellevis, F., Rijken, M., van der Hoek, L. and Korevaar, J. (2012) Determinants of increased primary health care use in cancer survivors. *J Clin Oncol*, 30(33):4155-4160.
12. Heins, M., Korevaar, J., Rijken, P. and Schellevis, F. (2013) For which health problems do cancer survivors visit their general practitioner? *Eur J Canc*, 49(1):211-8.
13. Hoekstra, R.A., Heins, M. J. and Korevaar, J.C. (2014) Health care needs of cancer survivors in general practice: a systematic review. *BMC Family Practice*, 15:94.
14. Iversen, L.H., Norgaard, M., Jacobsen, J., Laurberg, S. and Sorensen, H.T. (2009) The impact of comorbidity on survival of Danish colorectal cancer patients from 1995 to 2006—a population-based cohort study. *Dis Colon Rectum*, 5.
15. Jensen, H., Nissen, A. and Vedsted, P. (2014) Quality deviations in cancer diagnosis: prevalence and time to diagnosis in general practice. *Br J Gen Pract*, 64:e92-e98.
16. Khan, N.F., Watson, E. and Rose, P.W. (2011) Primary care consultation behaviours of long-term, adult survivors of cancer in the UK. *Br J Gen Pract*, 61(584):197-199.

17. Klabunde, C. N. et al. (2009) The Role of Primary Care Physicians in Cancer Care. *Journal of General Internal Medicine*, 24.9, 1029–1036.
18. Kousgaard, K.R., Nielsen, J.D., Olesen, F. and Jensen, A.B. (2003) General practitioner assessment of structured oncological information accompanying newly referred cancer patients. *Scand J Prim Health Care*, 21(2):110–4.
19. Land, L.H. et al. (2012) Influence of Comorbidity on the Effect of Adjuvant Treatment and Age in Patients with Early-Stage Breast Cancer. *British Journal of Cancer*, 107.11: 1901–1907.
20. Luengo-Fernandez, R., Leal, J., Gray, A. and Sullivan, R. (2013) Economic burden of cancer across the European Union: a population-based cost analysis. *Lancet Oncol*, 14:1165–1174.
21. McAvoy, B. (2007) General practitioners and cancer control. *Med J Aust* 187: 115–117.
22. McIlfatrick, S., Keeney, S., McKenna, H., McCarley, N. and McElwee, G. (2013) Investigating the role of the general practitioner in cancer prevention: a mixed methods study. *BMC Family Practice*, 14 (58).
23. National Cancer Registry (2015) Cancer in Ireland 1994-2013: Annual Report of the National Cancer Registry. NCR, Cork, Ireland.
24. Nord, C., Mykletun, A., Thorsen, L., Bjoro, T. and Fossa, S.D. (2005) Self-reported health and use of health care services in long-term cancer survivors. *Int J Cancer*, 114(2):307–16.
25. Ogle, K.S., Swanson, G.M., Woods, N., et al. (2000) Cancer and comorbidity: redefining chronic diseases. *Cancer*, 88:653–63.
26. Read, W.L., Tierney, R.M., Page, N.C., Costas, I., Govindan, R., Spitznagel, E.L. and Piccirillo, J.F. (2004) Differential prognostic impact of comorbidity. *J Clin Oncol*, 22.
27. Redaniel, M.T., Martin, R.M., Ridd, M.J., Wade, J. and Jeffreys, M. (2015) Diagnostic intervals and its association with breast, prostate, lung and colorectal cancer survival in England: historical cohort study using the Clinical Practice Research Datalink. *PLoS ONE*, 10(5).
28. Richards, M.A. (2009) The size of the prize for earlier diagnosis of cancer in England. *Br J Cancer*, 3; 101,2:S125-9.
29. Roorda, C., Bock, H., van der Veen, W.J., Lindeman, A., Jansen, L. and van der Meer, K. (2012) Role of the general practitioner during the active breast cancer treatment phase: an analysis of health care use. *Support Care Cancer*, 20, 705–714.
30. Rubin, G., Gildea, C., Wild, S., Shelton, J., Ablett-Spence, I. (2015) Assessing the impact of an English national initiative for early cancer diagnosis in primary care. *Br J Cancer*, 112:S57–S64.
31. Thomson, C. and Forman, D. (2009) Cancer survival in England and the influence of early diagnosis: what can we learn from recent EURO CARE results? *Br J Cancer* 101: S102–S109.
32. Vedsted, P. and Olesen, F. (2011) Are the serious problems in cancer survival partly rooted in gatekeeper principles? An ecologic study. *Br J Gen Pract*, 508–511.
33. Weaver, K. E., Forsythe, L. P., Reeve, B. B., Alfano, C. M., Rodriguez, J. L., Sabatino, S. A. Rowland, J. H et al. (2012). Mental and physical health-related quality of life among U.S. cancer survivors: Population estimates from the 2010 National Health Interview Survey. *Cancer Epidemiology, Biomarkers & Prevention*, 21, 2108–2117.
34. WHO (2011) *Global status report on noncommunicable diseases 2010* Geneva: World Health Organization.



The Irish College of General Practitioners (ICGP) is the professional body for general practice in Ireland. The College was founded in 1984 and is based in Lincoln Place, Dublin 2. The College's primary aim is to serve the patient and the general practitioner by encouraging and maintaining the highest standards of general medical practice. It is the representative organisation on education, training and standards in general practice.

**The Irish College of General Practitioners, 4/5 Lincoln Place, Dublin 2
Tel: 01-676 3705, Fax: 01-676 5850, Email: info@icgp.ie, Web: www.icgp.ie**