



National Cancer Control Programme Early Diagnosis of Symptomatic Cancer Plan 2022 – 2025



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Abbreviations

| CPD | Continous Professioal Development |
|------|---|
| EU | European Union |
| GP | General Practitioner |
| HCP | Health Care Professional |
| HSE | Health Service Executive |
| ICGP | Irish College of General Practitioners |
| MDC | Multi-disciplinary Diagnostic Centre |
| NCCP | National Cancer Control Programme |
| NCEC | National Clinical Effectiveness Committee |
| NCRI | National Cancer Registry of Ireland |
| NCS | National Cancer Strategy |
| NHS | National Health Service |
| NICE | National Institute for Health and Care Excellence |
| NMSC | Non-Melanoma Skin Cancer |
| NSS | National Screening Service |
| RAC | Rapid Access Clinic |
| ROI | Republic of Ireland |
| UK | United Kingdom |
| | |

Executive Summary

Diagnosing cancer early is a critical first step in achieving higher survival rates, reducing treatment severity and improving the quality of life of people living with cancer.¹ The **National Cancer Control Programme (NCCP) Early Diagnosis of Symptomatic Cancer Plan 2022-2025** aims to provide a strategic, comprehensive approach to increasing the proportion of symptomatic cancers that are diagnosed at early stage disease (stages I and II) in Ireland.

The Plan defines six high-level priority objectives (Figure 1) and the actions required to achieve these objectives. These objectives and actions will guide the overarching approach to delivery of the Early Diagnosis of Cancer Function, Community Oncology Division, NCCP.

Figure 1: Improving early diagnosis of symptomatic cancer in Ireland - objectives

- I. Strategic planning and collaboration Provide a strategic approach to improving the early diagnosis of symptomatic cancer in Ireland
- II. Empower people and communities to recognise and act on signs/symptoms of cancer
- III. Support community healthcare professionals to recognise and refer people with signs/ symptoms of cancer
- IV. Identify and address system factors that impact timeliness of diagnosis of symptomatic cancer
- V. Identify knowledge gaps and undertake research to inform development of early diagnosis initiatives
- VI. Monitor and evaluate the implementation and impact of the NCCP Early Diagnosis of Symptomatic Cancer Plan 2022-2025

Implementation of the Plan will primarily comprise a two-pronged approach. The objectives and actions outlined in the Plan will form the basis of

- I. Comprehensive programmes of work to enhance the early diagnosis of specific cancers/ tumour groups. Initial priority cancers for early diagnosis programmes of work will be chosen based on national policy – the National Cancer Strategy 2017-2026 highlights colorectal, breast and lung cancer as priorities for early diagnosis.
- **II.** Specific projects relevant to the early diagnosis of other cancers/tumour groups. These projects may relate to any of the objectives or actions of the plan and will proceed in parallel with comprehensive tumour-specific programmes of work.

Note: This Plan pertains to the early diagnosis of symptomatic cancer only. Early detection of asymptomatic cancer requires a different approach (surveillance of high-risk populations; population-based screening) and is not within the scope of this Plan.

The NCCP has a key role in the development of integrated cancer control and surveillance services for defined population subgroups with an inherited familial predisposition to cancer. However, this is beyond the scope of this Plan.

The National Screening Service (NSS) is responsible for the delivery of population-based cancer screening programmes in Ireland.

Introduction

1.1 Background

The National Cancer Control Programme (NCCP), established in 2007, is a Directorate of the Health Service Executive (HSE) with responsibility for the management, organisation and delivery of cancer care on a whole population basis. The NCCP is the lead agency with responsibility for delivering a number of recommendations of the National Cancer Strategy 2017-2026 (NCS)¹, including recommendations 7, 8 and 11, which pertain to the early diagnosis of cancer (Figure 2).

Figure 2: Recommendations of the National Cancer Strategy 2017-2026

Recommendation 7

The NCCP and the HSE Health & Wellbeing Directorate, in partnership with the voluntary sector, will develop a rolling programme of targeted multi-media based public awareness and education campaigns, aimed at the early detection of specific cancers and with particular focus on at-risk populations.

Recommendation 8

The NCCP, working with the ICGP and the National Clinical Effectiveness Committee, will develop a three year plan to enhance the care pathways between primary and secondary care for specific cancers. The plan will set out criteria for referral to diagnostics and incorporate the requirements for additional Rapid Access Clinics.

Recommendation 11

The NCCP, working with the other Directorates in the HSE, will develop criteria by end-2018 for the referral of patients with suspected cancer, who fall outside of existing Rapid Access Clinics, for diagnostic tests. The NCCP will ensure, through these criteria, that GPs will have direct access to cancer diagnostics within agreed timelines.

Several Divisions of the NCCP, including the Community Oncology Division and the Evidence and Quality Hub, have a role in delivering these recommendations. Internal cooperation and coordination are facilitated through the internal NCCP Early Diagnosis of Cancer Working Group (see Appendix A for Terms of Reference), which provides a forum for staff from different Divisions within the NCCP to discuss and collaborate on work relevant to the early diagnosis of cancer.

1.2 The Importance of Early Diagnosis of Cancer in Ireland

Diagnosing cancer early is a critical first step in achieving higher survival rates, reducing treatment severity and improving the quality of life of people living with cancer in Ireland¹. Additionally, early diagnosis of cancer is associated with significant cost savings for health and social care systems. While data specific to Ireland are lacking, a study undertaken by Cancer Research UK found that, if all areas in England diagnosed colon, ovarian, rectal and lung cancer as early as the best performing regions, this could save the National Health Service (NHS) over £44 million in treatment costs and benefit over 11,000 patients each year².

1.2.1 Cancer incidence

Approximately 44,000 incident cancer cases are diagnosed each year in the Republic of Ireland (ROI)³. Of these, just over one in two (c.24,000 cases per annum) are invasive cancers that are likely to require extensive treatment and significantly impact the lives of affected patients and their families. The remaining cases comprise non-melanoma skin cancers (NMSC) (27%) and non-invasive neoplasms (18%).

Figure 3 illustrates the estimated percentage and rank of the most commonly diagnosed invasive cancers (excluding NMSC) in Ireland, accounting for approximately 90% of all incident cases. Of these, the five most commonly diagnosed cancers – prostate, breast, colorectal, lung and melanoma skin cancer - account for approximately six out of every ten (58%) incident cases.

males females thyroid 0.6% Hodakin 0.6% Hodgkin 0.6% liver 1.0% testis 0.7% Hodgkin 0.6% other gynae⁺ 0.7% multiple myeloma 1.2% testis 1.3% thyroid 1.1% bladder 1.3% multiple myeloma 1.7% cervix 12% mouth & pharynx 1.4% multiple myeloma 1.5% liver 1.9% oesophagus 1.5% liver 1.5% brain & CNS 1.9% other gynae⁺ 1.6% ovary 1.6% pancreas 2.4% brain & CNS 1.7% brain & CNS 1.8% thyroid 1.7% oesophagus 2.6% bladder 2.0% stomach 1.7% oesophagus 2.1% bladder 2.7% leukaemia 1.8% mouth & pharynx 2.1% stomach 2.7% kidney 2.2% corpus uteri 2.2% leukaemia 2.8% stomach 2.3% pancreas 2.5% mouth & pharynx 2.8% leukaemia 2.3% cervix 2.6% pancreas 2.4% kidney 3.5% non-Hodgkin 3.3% kidney 2.9% ovary 3.4% non-Hodgkin 3.7% non-Hodgkin 3.6% corpus uteri 4.8% melanoma of skin 4.4% melanoma of skin 4.8% melanoma of skin 5.2% 11.1% lung lung 11.5% colorectal 10.1% 11.1% colorectal colorectal 12.1% 10.7% lung breast 14.7% 30.1% prostate 31.0% breast 16.0% prostate % of all invasive.... % of all invasive.... % of all invasive....

Figure 3: Estimated percentage and rank of the most commonly diagnosed invasive cancers (excluding non-melanoma skin cancer) in Ireland: annual average, 2017-2019³

Low-incidence invasive cancers are not shown (c.10%), therefore percentages do not sum to 100%. ⁺ Other gynaecological cancers: vulva, vagina, uterus (NOS) and placenta.

3 https://www.ncri.ie/sites/ncri/files/pubs/NCRI_Annual%20Report_2021.pdf

² https://news.cancerresearchuk.org/2014/09/22/half-of-cancers-diagnosed-at-late-stage-as-report-shows-early-diagnosis-saveslives-and-could-save/

1.2.2 Cancer mortality

Cancer is Ireland's leading cause of mortality, accounting for approximately one in three deaths (30.8%) in 2019 (Figure 4).⁴

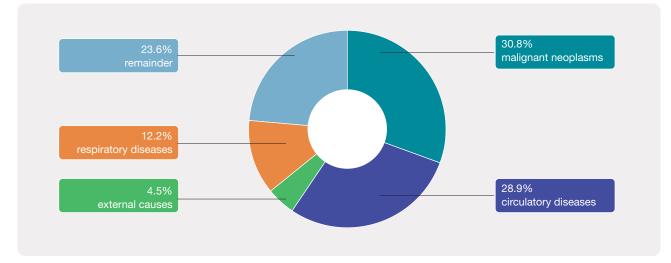


Figure 4: Principal causes of death in Ireland, 2019⁴

Figure 5 illustrates the estimated percentages and rank of the most common cancer deaths in Ireland. Lung cancer is Ireland's leading cause of cancer mortality in both males and females, causing one in five (20.7%) cancer deaths at population level.³ Breast (17.5%), colorectal (9.7%) and ovarian cancer (6.9%) are the second, third and fourth commonest causes of cancer deaths in females (Figure 5). Colorectal (12.2%), prostate (11.5%) and oesophageal cancer (5.9%) are the second, third and fourth commonest causes of cancer deaths in males (Figure 5).

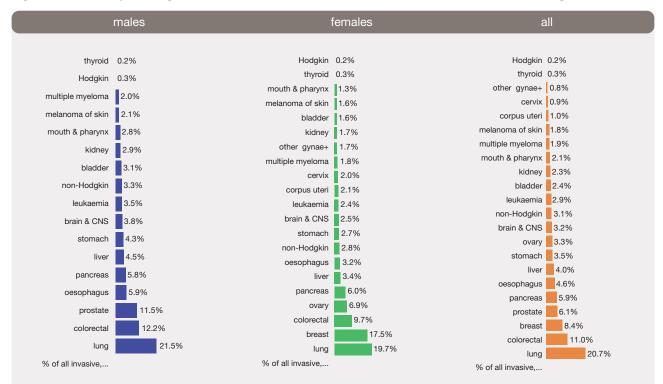


Figure 5: Estimated percentages and rank of the most common cancer deaths in Ireland: annual average, 2016-2018³

Cancers accounting for smaller percentages of cancer deaths (c.10% in total) are not shown, therefore percentages do not sum to 100%. Mortality data were provided by the Central Statistics Office (CSO).

1.2.3 Cancer survival

Cancer survival in Ireland continues to improve for all cancer types.⁵ During the diagnosis period 2014-2018, age-standardised 5-year net survival for all invasive cancers combined (excluding NMSC) was 65% (Figure 6 and Figure 7).⁵

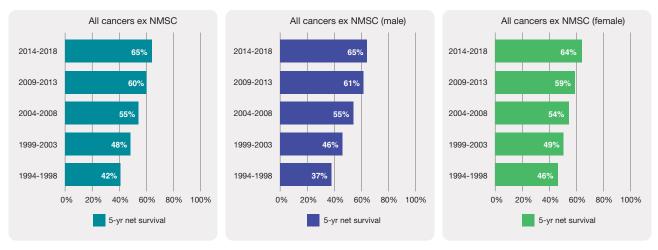
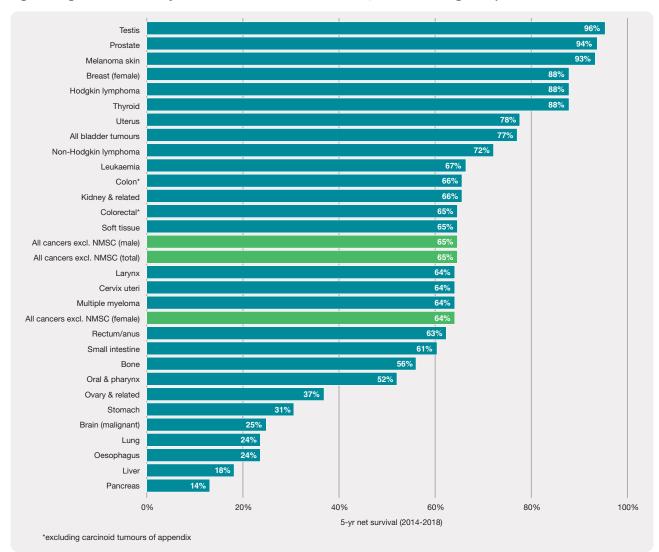


Figure 6: Age-standardised 5-year net survival for cancer In Ireland, 1994-2018⁵

Figure 7: Age-standardised 5-year net survival for cancer In Ireland, 2014 – 2018 diagnosis period⁵



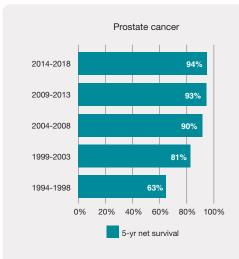
5 https://www.ncri.ie/sites/ncri/files/pubs/NCRI_Annual%20Report_2021.pdf

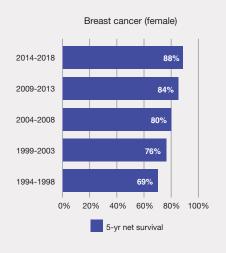
During the diagnosis period 2014-2018, 5-year net survival for the most commonly diagnosed cancers in Ireland (excluding NMSC) was

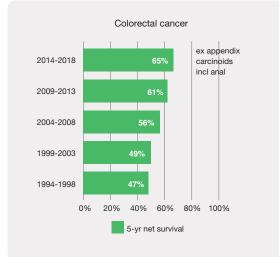
- Prostate cancer, 94%
- Breast cancer, 88%
- Colorectal cancer, 65%
- Lung cancer, 24%

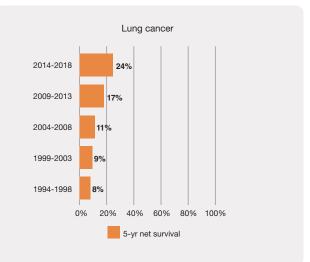
5-year survival for these major cancers has improved across successive diagnosis periods (Figure 8).6

Figure 8: Age-standardised 5-year net survival for prostate, breast, colorectal and lung cancer In Ireland, 1994-2018⁶









1.2.4 Cancer survival, International ranking

The CONCORD project provides global surveillance of 5-year net survival rates for cancer, which can be considered an indicator of timeliness of diagnosis and access to optimal treatment. The National Cancer Registry Ireland (NCRI) has contributed cancer survival data to this ongoing project since 1995. Figure 9 illustrates Ireland's rank within the European Union (EU) for 5-year net survival by cancer type and time period.⁷

| | 2000-2004 | 2005-2009 | 2010-2014 | top half 2010-2014? | rank comparison 2010-2014 vs. 2000-2004 |
|---|------------|------------|------------|------------------------|--|
| oesophagus | 5th of 22 | 3rd of 23 | 4th of 22 | yes 🗸 | \uparrow |
| stomach | 19th of 23 | 13th of 24 | 9th of 24 | yes 🗸 | \uparrow |
| rectum | 14th of 23 | 13th of 24 | 9th of 24 | yes 🗸 | \uparrow |
| pancreas | 12th of 22 | 12th of 23 | 8th of 23 | yes 🗸 | \uparrow |
| lung | 15th of 23 | 12th of 24 | 6th of 24 | yes 🗸 | \uparrow |
| melanoma skin | 9th of 23 | 10th of 24 | 8th of 24 | yes 🗸 | \uparrow |
| cervix | 18th of 23 | 21st of 24 | 16th of 24 | | \uparrow |
| prostate | 10th of 23 | 10th of 24 | 6th of 24 | yes 🗸 | \uparrow |
| brain – adults | 6th of 22 | 5th of 23 | 4th of 23 | yes 🗸 | \uparrow |
| brain – children | 11th of 21 | 12th of 20 | 7th of 22 | yes 🗸 | \uparrow |
| lymphoid – adults | 11th of 23 | 6th of 24 | 6th of 24 | yes 🗸 | 个 |
| acute lymphoblastic leukaemia – children | 11th of 23 | 11th of 23 | 10th of 23 | yes 🗸 | ^ |
| colon | 13th of 23 | 11th of 24 | 13th of 24 | | \leftrightarrow |
| breast | 16th of 23 | 15th of 24 | 16th of 24 | | \leftrightarrow |
| ovary | 23rd of 23 | 22nd of 24 | 23rd of 24 | | \leftrightarrow |
| liver | 8th of 23 | 10th of 23 | 9th of 23 | yes 🗸 | \downarrow |
| myeloid - adults | 3rd of 23 | 4th of 24 | 5th of 24 | yes 🗸 | \checkmark |
| lymphoma – children | 1st of 21 | 2nd of 21 | 4th of 21 | yes 🗸 | \checkmark |

Figure 9: Ireland's rank within the European Union for 5-year net survival by cancer type and period (CONCORD-3)

The figures in the table show Ireland's survival rank within the number of EU28 countries surveyed. For example, Ireland had the 4th highest survival for cancer of the oesophagus out of 22 countries surveyed during the period 2010-2014; Ireland ranked in the top half of the countries surveyed for cancer of the oesophagus during the period 2010-2014 and there was an improvement in survival rank (\uparrow) between the periods 2000-2004 and 2010-2014. Figures derived from Allemani et al (CONCORD-3, 2018)

The most recent wave of the CONCORD project (CONCORD-3) analysed survival data for the diagnosis period 2010-2014. Ireland ranked above the EU median for 5-year net survival for several major tumour types, including lung and prostate cancer (Figure 10 and Figure 11), but remained below the median for colon, breast, cervical and ovarian cancer (Figure 12 - 15).

Survival data must be interpreted with caution. For some major tumour types, e.g. breast cancer (Figure 13), 5-year survival is high across the EU, with a relatively narrow range between Ireland and the best-performing EU countries. For other tumour types, e.g. ovarian cancer (Figure 15), there is scope for significant improvement in survival rates in Ireland relative to other EU countries.

Additional caveats to the comparative analysis of survival data include variation in the quality and completeness of cancer registration data and follow-up between countries⁸, and the fact that relatively high survival for some cancers in some jurisdictions may reflect over diagnosis through population-based screening.⁹

The National Cancer Strategy 2017-2026¹ aims to ensure that cancer survival rates in Ireland are in the top quartile of European countries by 2025.

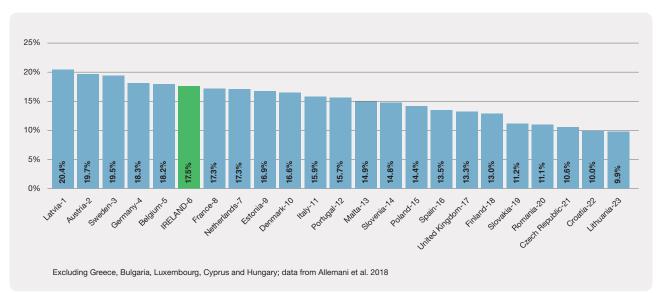


Figure 10: Cancer of the Lung: EU-28: 5-Year Net Survival and Rank (%): 2010-2014

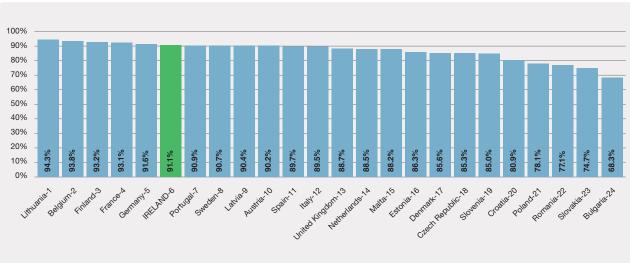


Figure 11: Cancer of the Prostate: EU-28: 5-Year Net Survival and Rank (%): 2010-2014

Excluding Greece, Luxembourg, Cyprus and Hungary; data from Allemani et al. 2018

⁸ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5879496/

⁹ https://www.karger.com/Article/FullText/503219#f01

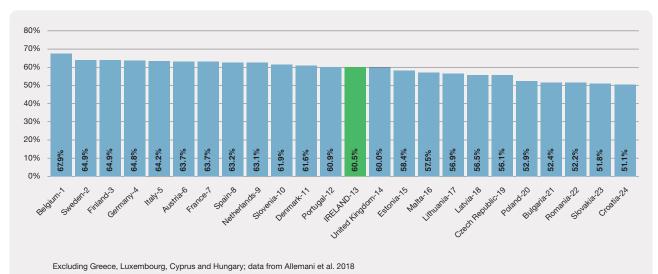
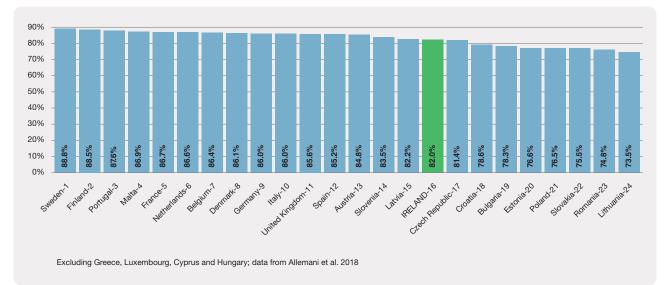


Figure 12: Cancer of the Colon, EU-28: 5-Year Net Survival and Rank (%): 2010-2014





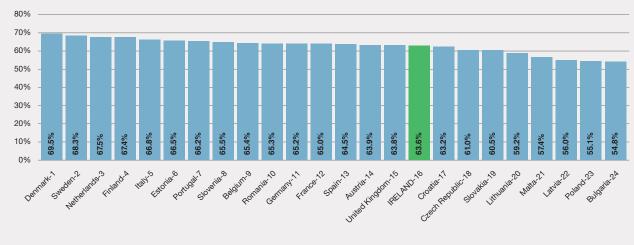
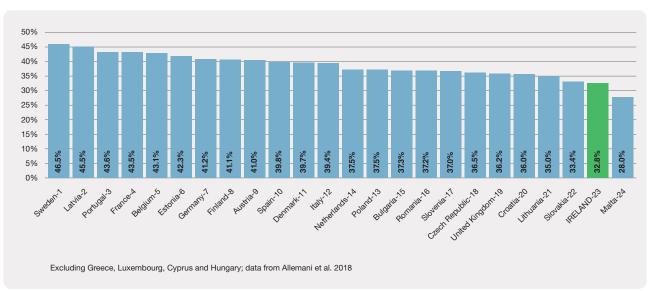


Figure 14: Cancer of the Cervix: EU-28: 5-Year Net Survival and Rank (%): 2010-2014

Excluding Greece, Luxembourg, Cyprus and Hungary; data from Allemani et al. 2018

Figure 15: Cancer of the Ovary: EU-28: 5-Year Net Survival and Rank (%): 2010-2014



1.2.5 Cancer survival by stage at diagnosis

For many cancers, stage at diagnosis is the most important determinant of survival. Figure 16 illustrates net survival by stage at diagnosis for six major cancer types in Ireland.¹⁰ Lung cancer is Ireland's leading cause of cancer mortality, but survival is greatly influenced by stage at diagnosis - 71% of patients diagnosed with stage I disease survive for at least one year post diagnosis, compared to just 16% of those diagnosed with stage IV disease (Figure 16). Five year survival for colorectal, breast and ovarian cancer is high for stage I disease (95%, 94% and 83% respectively), falling to just 10%, 19% and 15% respectively for stage IV disease (Figure 16).

| Cancer type | Survival at one year after diagnosis | | Survival at five years after diagnos | |
|-------------------|--------------------------------------|----------|--------------------------------------|----------|
| | Stage I | Stage IV | Stage I | Stage IV |
| Colorectal cancer | 98% | 49% | 95% | 10% |
| Lung cancer | 71% | 16% | 40% | 3% |
| Breast cancer | 99% | 48% | 94% | 19% |
| Prostate cancer | 99% | 78% | 93% | 36% |
| Pancreatic cancer | 37% | 14% | 17% | 4% |
| Ovarian cancer | 95% | 51% | 83% | 15% |

Figure 16: Survival at one and five years for cancers diagnosed in Ireland, 2008-2012; by stage at diagnosis¹⁰

10 https://www.gov.ie/en/publication/a89819-national-cancer-strategy-2017-2026/

1.2.6 Stage at diagnosis for common cancers in Ireland

Figure 17 illustrates percentage of late stage (III and IV) cancer diagnoses by site and year of diagnosis for all invasive cancers, and the four most commonly diagnosed invasive cancers (excluding NMSC), in Ireland between the years 1994-2013¹⁰. It is important to note that the apparent gradual increase in late stage cancer diagnoses for some tumour types is likely to be the result of stage migration, with improved diagnostic techniques and changes to staging systems resulting in classification of disease that would originally have been considered early stage into later stage categories.

As described in section 1.2.5, stage at diagnosis is the most important determinant of survival for most major tumour types. Increasing the proportion of cancers diagnosed early (stage I and II) is a key first step in improving cancer survival in Ireland.

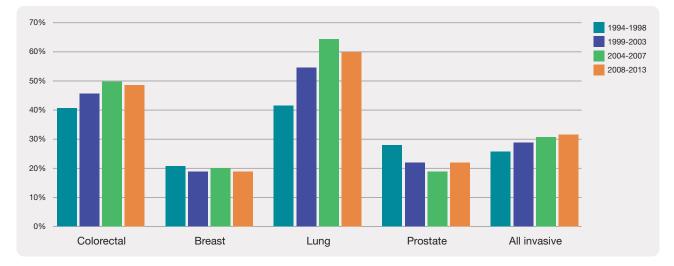


Figure 17: Percentage of late stage (III and IV) cancer diagnoses by site and year of diagnosis¹⁰

1.3 Current and Future Challenges

1.3.1 Projected cancer incidence, 2045

Cumulative lifetime risk of being diagnosed with an invasive cancer for the population living in Ireland is 1:2. If age-specific risk of being diagnosed with cancer remains unchanged, the incidence of invasive cancer (excluding NMSC) in males and females is expected to increase by 111% and 84% respectively between 2015 and 2045, resulting in a total of 43,000 cases per annum by 2045¹¹ (Figure 18).



Figure 18: Projected increase in invasive cancers, excluding NMSC, to year 2045¹¹

The figures for 2015 represent the number of cases observed in that year. The figures for 2020, 2025, 2030, 2035, 2040 and 2045 are projections. The percentages are the increase on the observed 2015 case count.

11 https://www.ncri.ie/sites/ncri/files/pubs/CancerIncidenceProjections_NCRI_fullreport_09042019_final.pdf

If this projected increase is realised, the impact on society, and on health and social care systems, will be considerable. Population demographics, with a growing and aging population, will inevitably result in increased cancer incidence into the future. However, this increase can be minimised through an enhanced and sustained focus on cancer prevention. Where cancer does occur, its impact can be significantly mitigated through early diagnosis. Early diagnosis of cancer, before it has grown, locally advanced or metastasised, offers increased chances of curative treatment and optimal health outcomes for patients, in addition to cost savings for health and social care systems.¹²

1.3.2 COVID-19 Pandemic

The COVID-19 pandemic has had a significant impact on cancer diagnosis and treatment in Ireland and internationally, particularly in 2020. Despite sustained commitment to maintaining cancer services throughout the pandemic, Irish data demonstrate an overall reduction in activity across most domains (including presentation, diagnosis and treatment) in 2020 relative to 2019.¹³ The impact of the pandemic in terms of stage at diagnosis and patient outcomes will only be fully understood when validated National Cancer Registry Ireland (NCRI) data are available.

1.4 Aim of Plan

Improving early diagnosis of cancer is an ongoing, long-term goal and this Plan will build on the significant body of work undertaken to date.

This plan aims to provide a strategic, comprehensive approach to increasing the proportion of symptomatic cancers that are diagnosed at early stage disease (stages I and II) in Ireland

¹² https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4385969/

¹³ https://www.rcpi.ie/news/releases/rcpi-faculty-of-pathology-launches-new-report-on-cancer-care-during-covid-19-pandemic/

Developing the Plan

This Plan was developed to

- Provide a strategic approach to improving the early diagnosis of symptomatic cancer in Ireland, including through delivery of the relevant recommendations of the National Cancer Strategy 2017-2026
- Build on previous work in the area of early diagnosis of cancer
- Mitigate the impact of the COVID-19 pandemic
- Consolidate and operationalise learning from the COVID-19 pandemic towards ensuring a resilient service for the population of Ireland

The Plan was developed using a 'whole-of system approach' to harness the input of the many stakeholders with a role to play in improving the early diagnosis of cancer in Ireland. The step-by-step process employed to develop the NCCP Early Diagnosis of Symptomatic Cancer Plan is outlined in Table 1.

Table 1: Process to develop the NCCP Early Diagnosis of Symptomatic Cancer Plan, 2022-2025

- Establishment and development of the Early Diagnosis of Cancer Function, Community Oncology Division, NCCP
- Review of work conducted by NCCP Early Detection of Cancer Advisory Group pre-COVID (December 2018 – March 2020)
- Literature review to define the factors that influence the early diagnosis of symptomatic cancer
- Review of national and international practice to inform development of high level objectives and actions
- Draft Plan
- Internal consultation with NCCP Early Diagnosis Working Group and Executive Management Team
- External stakeholder and public consultation
- NCCP Executive Management Team review and sign off

Factors that influence the early diagnosis of symptomatic cancer

Factors that influence the early diagnosis of symptomatic cancer can be broadly categorised into four groups - disease factors, patient factors, healthcare professional (HCP) factors and health system factors (Table 2).

| I. Disease Factors | II. Patient Factors | III. HCP Factors | IV. Health System Factors |
|--|---|---|---|
| Tumour biology Natural history of disease | Knowledge of signs and symptoms Health literacy Attitudes towards cancer Access to healthcare Knowledge of how to access healthcare Health seeking behaviour Socio-economic deprivation | Knowledge of signs and symptoms Index of suspicion Attitudes towards cancer Access to diagnostics Referral guidelines and pathways Knowledge and awareness of referral guidelines and pathways | Model of healthcare system Funding, human and capital resources Configuration of services, referral guidelines and pathways and the role and scope of practice of primary and secondary healthcare professionals Access to diagnostics |

Table 2: Factors that influence the early diagnosis of symptomatic cancer

I. Disease factors

• Tumour biology

- Anatomical location of primary tumour.
- Aggressiveness of cancer this is influenced by factors including histological subtype.

• Natural history of the disease

- Signs/symptoms/non-diagnostic test findings at early stage of disease.

The National Institute for Health and Care Excellence (NICE) GP Cancer Referral Guidelines [NG12] recommend that patients should be referred for investigation if they have signs/symptoms with a positive predictive value of >/= 3% for cancer.¹⁴ The threshold is lower for children. Ultimately, 97% of patients who are investigated on this basis will be reassured that they do not have cancer.

II. Patient factors

- Knowledge and awareness of the signs and symptoms of disease and their clinical significance.
 - Patients who can recognise clinical features suspicious of cancer, and who seek early medical intervention, are generally more likely to have less advanced disease and better prospects for treatment.¹⁵
- **Health literacy** is the ability to obtain, read, understand and use healthcare information. The EU Health Literacy Survey (2012) showed that 40% of Irish adults had limited health literacy.¹⁶
- Attitudes towards cancer influence health seeking behaviour.
- Access to healthcare.
- Knowledge of how to access healthcare.
- Health seeking behaviour is defined as "any action or inaction undertaken by individuals who perceive themselves to have a health problem or to be ill for the purpose of finding an appropriate remedy."¹⁷
- Socio-economic deprivation
 - There is only limited evidence of variation in stage at presentation with area level deprivation, including lower proportions of early-stage breast and prostate cancer among more deprived populations. However, there is incontrovertible evidence of the impact of socio-economic status and deprivation on death rates from some cancers in Ireland. The causes are multi-factorial, ranging from smoking prevalence and dietary factors to inadequate access to timely diagnostics.¹⁸

¹⁴ https://www.nice.org.uk/guidance/ng12/resources/suspected-cancer-recognition-and-referral-pdf-1837268071621

¹⁵ https://assets.gov.ie/9315/6f1592a09583421baa87de3a7e9cb619.pdf

¹⁶ https://www.nala.ie/wp-content/uploads/2019/08/NALA-Factsheet-Health-literacy-in-Ireland.pdf

¹⁷ Olenja J. Editorial Health seeking behaviour in context. 2004.

¹⁸ https://assets.gov.ie/9315/6f1592a09583421baa87de3a7e9cb619.pdf

III. Healthcare professional (HCP) factors

• Knowledge of the signs and symptoms of disease and their clinical significance

- While GPs treat thousands of patients each year, each GP in Ireland will, on average, have just eight patients in their practice newly diagnosed with cancer each year.¹⁹ Approximately 85% of cancer patients present with symptomatic disease, and primary healthcare professionals, including GPs, practice nurses, dentists, pharmacists and public health nurses, have a key role in assessing these symptoms and advising/referring appropriately.¹⁹
- Appropriate index of suspicion
 - GP clinical suspicion is a key enabler of the early diagnosis of cancer, including among patients that present with vague, non-specific or atypical symptoms. Danish and UK data suggest that up to 50% of cancer patients present in such a manner, with vague, non-specific or atypical symptoms that would not trigger an urgent referral under existing NICE guidelines.²⁰ A UK study of results from five multidisciplinary diagnostic centre (MDC) projects for non-specific but concerning symptoms possibly indicative of cancer found that GP clinical suspicion was a highly significant predictor of cancer in this cohort (p=0.006).²¹
- Attitudes towards cancer
- Direct, timely GP access to diagnostics
- **Defined referral guidelines and pathways** with timely access to specialist review and/or further diagnostic evaluation.
- Knowledge and awareness of referral guidelines and pathways

IV. Health system factors

- **Model of healthcare system** i.e., Beveridge model, Bismarck model, national health insurance model, out-of-pocket model. It is very important to consider the tangible and intangible barriers and enablers to medical care that a healthcare system presents to the overall population and sub-groups of that population. For example, cost may present a barrier to accessing primary care for people who are not eligible for the General Medical Scheme (GMS) in Ireland.
- Sufficient funding, and human and capital resources are required to deliver an optimal service across the cancer continuum. This includes sufficient infrastructure, sufficient numbers and geographic distribution of GPs to ensure timely access to primary care for the population, sufficient numbers of radiologists, radiographers, ultrasonographers and diagnostic machinery and equipment to provide timely diagnostic services, sufficient numbers of secondary care physicians to provide timely specialist review and treatment.
- Configuration of services, referral guidelines and pathways and the role and scope of practice of primary and secondary healthcare professionals. Configuration of services and referral guidelines/ pathways between primary and secondary care impact timeliness of diagnosis of symptomatic cancer. Integrated, as opposed to siloed, models of care facilitate early diagnosis.

¹⁹ https://www.gov.ie/en/publication/a89819-national-cancer-strategy-2017-2026/

^{20 &}lt;u>https://www.dovepress.com/transforming-cancer-outcomes-in-england-earlier-and-faster-diagnoses-p-peer-reviewed-fulltext-article-JHL</u>

²¹ https://www.nature.com/articles/s41416-020-0947-y

The 'gatekeeper' function of primary care should be considered. Evidence demonstrates that cancer survival rates are lower, and referral to secondary care is delayed, in countries with a strong primary care 'gatekeeper' role.²²

The role and scope of practice of primary and secondary healthcare professionals influences time to diagnosis. An expanded role for GPs, and recognition/expansion of the key role and scope of practice of other primary care providers (e.g. dentists, public health nurses, community pharmacists) could facilitate early diagnosis.

- Direct, timely GP access to diagnostics with clear referral criteria.
- Clear referral guidelines and pathways with timely access to further diagnostic evaluation and/ or specialist review. It is important to also consider IT systems and mechanisms of referral – e.g. electronic versus fax/paper-based etc.

The stage at which symptomatic cancer is diagnosed is influenced by the complex interplay between these factors. Increasing the proportion of symptomatic cancers that are diagnosed at early stage disease involves defining and addressing the contributing factors for a given tumour type.

²² Harrison CJ, Spencer RG, Shackley DC. Transforming cancer outcomes in England: earlier and faster diagnoses, pathways to success, and empowering alliances. J Healthc Leadersh. 2019;11:1-11 <u>https://doi.org/10.2147/JHL.S150924</u>

This Plan aims to provide a strategic, comprehensive approach to increasing the proportion of symptomatic cancers that are diagnosed at early stage disease (stages I and II) in Ireland.

4.1 Objectives

The plan's objectives are

- I. Strategic planning and collaboration Provide a strategic approach to improving the early diagnosis of symptomatic cancer in Ireland
- II. Empower people and communities to recognise and act on signs/symptoms of cancer
- III. Support community health care professionals to recognise and refer people with signs/symptoms of cancer
- IV. Identify and address system factors that impact timeliness of diagnosis of symptomatic cancer
- V. Identify knowledge gaps and undertake research to inform development of early diagnosis initiatives
- VI. Monitor and evaluate the implementation and impact of the NCCP Early Diagnosis of Symptomatic Cancer Plan 2022-2025

4.2 Actions

The actions required to achieve each objective are detailed below.

Objective I. Strategic planning and collaboration - Provide a strategic approach to improving the early diagnosis of symptomatic cancer in Ireland

| Ref | Action | Lead Responsibility | Partners |
|-----|---|---------------------|--|
| la | Constitute an internal NCCP Early Diagnosis of Cancer Working Group to facilitate collaborative working within NCCP | NCCP | N/A |
| lb | Develop a prioritisation framework to guide the prioritisation of cancers for the design and implementation of early diagnosis programmes of work | NCCP | N/A |
| lc | Convene an <i>Early Diagnosis of Symptomatic Cancer</i> <i>Working Group</i> to collaborate in delivery of the NCCP Early Diagnosis of Symptomatic Cancer Plan 2022-2025 | NCCP | Internal and external stakeholders |

Objective II. Empower people and communities to recognise and act on signs/ symptoms of cancer

| Ref | Action | Lead Responsibility | Partners |
|-----|--|---------------------|--|
| lla | Identify national and target population barriers | NCCP | Department of Health, |
| | to recognising and acting on signs/symptoms of cancer | | NCRI, |
| | Barriers may relate to | | HSE Health and Wellbeing, |
| | Knowledge of signs and symptoms | | Voluntary Sector, |
| | Health literacyAttitudes towards cancer | | HSE Departments of Public Health, |
| | Access to healthcare | | HSE Social Inclusion, |
| | Knowledge of how to access healthcare | | Community Organisations, |
| | Health seeking behaviour Socio-economic deprivation | | Organisations that advocate for and support minority/ marginalised cohorts, |
| | | | Primary HCPs, |
| | | | Public/patients |
| llb | Work with stakeholders to design and deliver interventions to address barriers to recognising and acting on signs/symptoms of cancer | NCCP | Department of Health, HSE Health and Wellbeing, |
| | | | Voluntary Sector |
| | | | HSE Departments of Public Health, |
| | | | HSE Social Inclusion, |
| | | | Community Organisations, |
| | | | Organisations that advocate for and support minority/ marginalised cohorts, |
| | | | Primary HCPs, |
| | | | Public/patients |
| llc | Develop and maintain a dedicated 'early diagnosis of cancer' webpage on the NCCP website, offering evidence-based information and resources for the public/patients | NCCP | HSE Digital |

Objective III. Support community health care professional to recognise and refer people with signs/symptoms of cancer

| Ref | Action | Lead Responsibility | Partners |
|------|--|---------------------|---|
| Illa | Identify community HCP barriers to recognising and referring people with signs/symptoms of cancer | NCCP | Organisations that deliver |
| | Barriers may relate to | | training/continous profressional |
| | Knowledge of signs and symptoms | | development |
| | Index of suspicion | | (CPD) to primary HCPs, |
| | Attitudes towards cancer | | Organisations that |
| | Access to diagnostics | | develop/deliver |
| | Referral guidelines and pathways Knowledge and awareness of referral guidelines and pathways | | HCP educational content via any medium (including periodicals), |
| | | | Primary HCPs, |
| | | | Academia |
| IIIb | Work with stakeholders to design and deliver interventions to address HCP barriers to recognising and referring people with signs/symptoms of cancer | NCCP | Organisations that deliver training/ CPD to primary HCPs, |
| | | | Organisations that develop/deliver HCP educational content via any medium (including periodicals), |
| | | | Primary HCPs, |
| | | | Academia |
| IIIc | Develop and maintain a dedicated 'early diagnosis of cancer' webpage on the NCCP website, offering evidence-based information and resources for HCPs | NCCP | HSE Digital |

Objective IV. Identify and address health system factors that impact timeliness of diagnosis of symptomatic cancer

| Ref | Action | Lead Responsibility | Partners |
|-----|--|---|---|
| IVa | Identify health system factors that impact timeliness of diagnosis of symptomatic cancer Relevant system factors may include Model of healthcare system Funding, human and capital resources Configuration of services, referral guidelines and pathways and the role and scope of practice of primary and secondary healthcare professionals Access to diagnostics | NCCP, Department of Health, HSE Leadership | NCRI, HSE Directorates, NCEC, Community Diagnostics Steering Group, HSE Radiology Programme, HSE Endoscopy Programme, HSE Integrated Care Programmes, Physicians and allied HCPs with role in assessment, referral and treatment of cancer patients, Public/patients |
| IVb | Work with stakeholders to design and deliver interventions to address health system factors that impact timeliness of diagnosis of symptomatic cancer | NCCP, Department of Health, HSE Leadership | NCRI, HSE Directorates, NCEC, Community Diagnostics Steering Group, HSE Radiology Programme, HSE Endoscopy Programme, HSE Integrated Care Programmes, Physicians and allied HCPs with role in assessment, referral and treatment of cancer patients, Public/patients |
| IVc | Identify systemic inequities impacting timeliness of diagnosis of symptomatic cancer for defined patient cohorts and design/contribute to/advocate for interventions towards ensuring equitable service provision | NCCP | Department of Health, NCRI, HSE Social Inclusion, Voluntary Sector, Community Organisations, Organisations that advocate for and support minority/ marginalised cohorts, HSE Public Health, Primary HCPs, Public/patients |

Objective V. Identify knowledge gaps and undertake research to inform development of early diagnosis initiatives

| Ref | Action | Lead Responsibility | Partners |
|-----|--|---------------------|---|
| Va | Identify knowledge gaps relevant to the early diagnosis of cancer | NCCP | Department of Health, |
| | | | International stakeholder organisations, |
| | | | NCRI, |
| | | | Academia, |
| | | | Clinicians and allied HCPs involved in service delivery, |
| | | | Voluntary Sector, |
| | | | HSE Public Health, |
| | | | Public/patients |
| Vb | Undertake, commission and support research to address knowledge gaps and inform development and implementation of early diagnosis initiatives | NCCP | Department of Health, International stakeholder organisations, NCRI, |
| | | | Academia, |
| | | | Clinicians and allied HCPs involved in service delivery, |
| | | | Voluntary Sector, |
| | | | HSE Public Health, |
| | | | Public/patients |

Objective VI. Monitor and evaluate the implementation and impact of the NCCP Early Diagnosis of Symptomatic Cancer Plan, 2022-2025

| Ref | Action | Lead Responsibility | Partners |
|-----|---|---------------------|--|
| Vla | Develop a monitoring and evaluation framework for the NCCP Early Diagnosis of Symptomatic Cancer Plan 2022-2025 | NCCP | NCCP Early Diagnosis of Symptomatic Cancer Working Group |
| Vlb | Publish an annual report to update on the implementation and impact of the Plan | NCCP | NCCP Early Diagnosis of Symptomatic Cancer Working Group |
| Vlc | Incorporate recommendations from annual report into work plan for following year | NCCP | NCCP Early Diagnosis of Symptomatic Cancer Working Group |

Implementation

5.1 How will the Plan be implemented?

The NCCP will lead and co-ordinate delivery of the Plan. The initial priority is delivery of the actions described under Objective I (strategic planning and collaboration) as these are key enablers of delivery of the remaining objectives of the Plan. Following delivery of these actions, implementation of the Plan will comprise a two-pronged approach

- I. Objectives II-VI, and associated actions, will form the basis of comprehensive programmes of work to enhance the early diagnosis of specific cancers/tumour groups. Following a decision to focus on a particular cancer/tumour group, the action areas under objectives II-VI of this Plan will be used to design a comprehensive programme of work to improve early diagnosis of that cancer/tumour group, which will include
 - Initiatives to empower people and communities to recognise and act on signs/symptoms of cancer, e.g. awareness campaigns (Objective II)
 - Initiatives to support community healthcare professionals to recognise and refer people with signs/ symptoms of cancer, e.g. educational interventions (Objective III)
 - Identifying and addressing system factors that impact timeliness of diagnosis of symptomatic cancer, e.g. revision of existing referral guidelines/pathways or development of new guidelines/pathways (Objective IV)
 - Identifying knowledge gaps and undertaking research to inform development of early diagnosis initiatives (Objective V)
 - Monitoring and evaluation of the implementation and impact of the Plan (Objective VI).

Once the programme of work for an individual cancer/tumour group has been defined, timelines and outcome measures for each action, and for the overall programme of work, can be agreed.

The design and delivery of a comprehensive programme of work to enhance the early diagnosis of a specific cancer/tumour group will be a complex, long-term undertaking that will involve defining and addressing the many factors that influence the timelines of diagnosis of symptomatic cancer. Initial priority cancers for early diagnosis programmes of work will be chosen based on national policy – the National Cancer Strategy 2017-2026 highlights colorectal, breast and lung cancer as priorities for early diagnosis. A Framework for Prioritising Cancers for Early Diagnosis Programmes of Work will be developed by the NCCP (Objective I, Action Ib) to guide the decision-making process, ensuring that evidence-based criteria are considered.

II. Specific projects relevant to the early diagnosis of other cancers/tumour groups will proceed in parallel with comprehensive programmes of work. These projects may relate to any of the objectives and actions defined in the Plan. The NCCP or its stakeholders may identify the need for such projects.

5.2 Who will implement the Plan?

The NCCP will lead and co-ordinate delivery of the Plan.

The NCCP will convene a multi-agency Early Diagnosis of Symptomatic Cancer Working Group (Objective I, Action Ic) to promote collaborative working towards delivering the objectives and actions of the Plan.

Monitoring and evaluation

Objective VI will form the basis for monitoring and evaluation of the implementation and impact of the NCCP Early Diagnosis of Symptomatic Cancer Plan. Tumour-specific early diagnosis programmes of work and parallel projects related to other cancers/tumour groups will be reported separately. Timelines and outcome measures for each action delivered under the Plan will be clearly defined wherever possible. Quantifying the relative impact of individual actions on stage at diagnosis of a given tumour type will not be possible. This is because there are many caveats to inferring a causal relationship between an intervention (e.g. a public awareness campaign about the signs and symptoms of cancer) and an outcome (e.g. an increase in the proportion of cancer diagnosed at early stage disease). Timely access to relevant data presents an additional challenge, with a significant time lag in reporting of cancer incidence and staging data by the National Cancer Registry Ireland (NCRI), in line with international standards. However, wherever possible, appropriate outcome measures will be defined to assess the impact of individual actions delivered under the Plan.

Conclusion

Cancer is the leading cause of death in Ireland. Diagnosing cancer at its earliest possible stage is a crucial first step to achieving higher survival rates and improving the quality of life of people living with cancer. This plan provides a strategic, comprehensive approach to increasing the proportion of symptomatic cancers diagnosed at early stage disease in Ireland. Early diagnosis is influenced by a complex combination of disease factors, patient factors, healthcare professional factors and health system factors. Empowering people and communities to recognise and act on signs and symptoms of cancer, including through public awareness campaigns, is a critical step towards improving early diagnosis. An additional priority involves supporting community healthcare professionals to recognise and refer people with signs and symptoms of cancer. This can be achieved through interventions such as educational initiatives. At a health system level, factors that influence timeliness of symptomatic cancer diagnosis, including referral guidelines and pathways, must be defined and addressed. Knowledge gaps should be identified and addressed to ensure that the needs of the population are met through data-driven, evidence-based interventions.

NCCP looks forward to collaborating with our many stakeholders to deliver the Early Diagnosis of Symptomatic Cancer Plan 2022-2025, towards improving cancer outcomes for the population of Ireland.

Appendices

Appendix A: Internal NCCP Early Diagnosis of Cancer Working Group – Terms of Reference

Terms of Reference

Internal National Cancer Control Programme Early Diagnosis Working Group

Purpose

The purpose of the Working Group is to facilitate collaborative working between internal stakeholders within the NCCP towards delivering the recommendations and key performance indicators (KPIs) of the National Cancer Strategy (NCS) 2016-2027 that pertain to the early diagnosis of symptomatic cancer. These recommendations and KPIs include:

Recommendation 7: The NCCP and the HSE Health & Wellbeing Directorate, in partnership with the voluntary sector, will develop a rolling programme of targeted multi-media based public awareness and education campaigns, aimed at the early detection of specific cancers and with particular focus on at-risk populations.

Recommendation 8: The NCCP, working with the ICGP and the National Clinical Effectiveness Committee, will develop a three year plan to enhance the care pathways between primary and secondary care for specific cancers. The plan will set out criteria for referral to diagnostics and incorporate the requirements for additional Rapid Access Clinics.

Recommendation 11: The NCCP, working with other Directorates in the HSE, will develop criteria by end-2018 for the referral of patients with suspected cancer, who fall outside of existing Rapid Access Clinics, for diagnostic tests. The NCCP will ensure, through these criteria, that GPs will have direct access to cancer diagnostics within agreed timelines.

KPI 2: Introduce cancer awareness campaigns for specific diseases (e.g. lung cancer). Achieve a 15% relative increase in the percentage of lung cancers diagnosed at Stage I and II one year following awareness campaign.

KPI 4: Increase the proportion of cancers diagnosed early. Achieve a 10% relative increase on 2013 figures in the percentage of colorectal, breast and lung cancers diagnosed at Stage I and II by 2020.

KPI 7: Reduce the proportion of cancers detected in Emergency Departments. Achieve a 50% relative decrease over 2013 figure in the percentage of cancers diagnosed in Emergency Departments by 2026.

Aim

Facilitate collaborative working within NCCP towards delivering the recommendations and KPIs of the NCS that pertain to the early diagnosis of symptomatic cancer, including recommendations 7, 8 and 11 and KPIs 2, 4 and 7.

Objectives

- The Community Oncology division will lead delivery of Recommendation 7 the content of awareness and education campaigns will be informed by criteria for referral to diagnostics for a given cancer, as referenced in Recommendations 8 and 11.
- The Evidence and Quality Hub will lead delivery of Recommendation 8.
- The Community Oncology and Evidence and Quality Hub will work together to deliver Recommendation 11.

Early Diagnosis Working Group Membership

This is an internal NCCP Working Group. In addition to the core membership, additional input may be sought from within the NCCP on an ad hoc basis.

Members

Chair - Dr Heather Burns, Specialist in Public Health Medicine, NCCP.

Dr Una Kennedy, GP Advisor to NCCP.

Ms Aine Lyng, Cancer Prevention Officer, NCCP.

Dr Triona McCarthy, Assistant National Director, Head of Community Oncology, Specialist in Public Health Medicine, NCCP.

Dr Eve O'Toole, Head of Evidence and Quality Hub, NCCP.

Ms Fiona Bonas, Assistant National Director, Head of Quality and Safety, NCCP.

Ms Eileen Nolan, National Programme Manager for Urological, Children, Adolescents/ Young Adults (CAYA) Cancers and GP Cancer E-Referral Systems, NCCP.

Membership Expectations

- Actively participate in achieving the aims and objectives of the Working Group;
- Communicate openly in relation to planned/ongoing Early Diagnosis work;
- Offer feedback on planned/ongoing Early Diagnosis work being undertaken by colleagues within NCCP;
- Attend meetings whenever possible. If unable to attend a meeting, please send apologies at least 24 hours in advance of the meeting and consider nominating an alternate to attend if appropriate.

Meeting location, frequency and admin support:

Meeting location will be dictated by Public Health advice in relation to the ongoing COVID-19 pandemic. Meetings will be held remotely for the foreseeable future. When Public Health guidance allows, meeting may be held on site in NCCP offices. Videoconferencing/teleconferencing facilities will be available for those who cannot attend in person.

Meetings will be held monthly.

Brief notes/action points will be circulated after each meeting.