IPH response to Department of Health Consultation on the Cancer Strategy for Northern Ireland 2021-2031

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Synopsis of IPH submission

Introduction

The Institute of Public Health informs public policy to support healthier populations in the Republic of Ireland and Northern Ireland.

Our key priorities are promoting health and wellbeing, improving health equity, and reducing health inequalities through evidence, policy, and partnership.

This submission was made in response to a consultation, launched by the Department of Health in Northern Ireland in October 2021, on developing a new 10-year cancer strategy.

It focuses on four key themes: cancer prevention, diagnosis and treatment, patient experience and strategy implementation in Northern Ireland.

Key Observations

In this submission, the Institute made a series of recommendations, including the benefits of investing in cancer prevention and reduction of modifiable risk factors, the need for a clear roadmap for transformational change, greater collaboration and knowledge sharing with Great Britain and Ireland, and the need to address and reduce health inequalities.

The Institute also highlighted the need to improve health literacy and communications around cancer, and to address systematic barriers to cancer care. A programme of research to gather intelligence on the underlying reasons for low cancer survival would be welcomed to identify salient intervention points and inform prioritisation.

The Institute also highlighted the need for learning from the pandemic and investment in the resilience of the service against future public health threats.

IPH Response / Submission

5. Strategic Direction for Cancer Services in Northern Ireland.
Do you agree that the proposals set out in the Cancer Strategy Consultation paper are the correct strategic priorities for Cancer services in Northern Ireland?

The Institute welcomes the development of a new cancer strategy in Northern Ireland. We have provided commentary on ten key issues relating to the proposed strategic direction below.

Ensuring strategic leadership for cancer prevention and a reasonable balance between prevention and service development

Cancer incidence is increasing, with large increases predicted over the next 20 years. We welcome the identification of cancer prevention as a central area of action within the strategic direction. We also welcome the commitment to addressing health inequalities, as evidenced both in the Minister's Foreword and on page 15 of the Cancer Strategy Consultation paper. There is substantial scope for prevention through the implementation of evidence-based prevention strategies (World Health Organization, 2021).

However, the Cancer Strategy Consultation paper is heavily weighted towards service development in the treatment and disease management domains, whereas the strategic responsibility for cancer prevention is largely delegated into other strategies. This may result in a lack of integration, ownership and oversight on the cancer prevention agenda, and position it outside the 'core business' of the cancer strategy. The level of detail presented in respect of specific cancer services may sit better in a service review to support the overall strategy and inform implementation, rather than in the strategy itself.

Whilst we recognise the importance of service development in reducing mortality and improving outcomes including quality of life, risk reduction has the potential to prevent approximately half of all cancers (Seventieth World Health Assembly, 2017). There is an opportunity in this strategy to prioritise the reduction of modifiable risk factors and invest in the determinants of health across the life-course[1], improve health and reduce health inequalities.

Committing to a clear roadmap for transformational change including specific and measurable goals

The need for transformational change is evident in the Cancer Strategy Consultation paper, however there is limited detail on how change will be achieved. The driver diagram is helpful to understand how the Department envisage these aims might be

[1] The life-course approach aims at increasing the effectiveness of interventions throughout a person's life. It focuses on a healthy start to life and targets the needs of people at critical periods throughout their lifetime. It promotes timely investments with a high rate of return for public health and the economy by addressing the causes, not the consequences, of ill health (World Health Organization Regional Office for Europe).

achieved, but there is no clear roadmap to outline the actions required for strategy implementation, timeline, prioritisation, or reference to change management models to support the process. More detail on the timings and sequencing for delivering the recommendations listed in the Cancer Strategy Consultation paper would be beneficial, including identifying any interdependencies.

A logic model/theory of change diagram specifying the high-level inputs, processes, outputs and outcomes may support shared understanding on the aims of the strategy, promote buy-in and assist with process and outcome evaluation. The Health Service Executive guidelines on change management in health services (Health Service Executive; Human Resources Division; Organisation Development and Design, 2018) may be of use, which are based on an organisation-development approach and founded on principles of co-production, acknowledging that people who receive and deliver services are best positioned to guide change.

Challenges with evaluating targets from the 2008 strategy have also been raised in discussions within the Northern Ireland Assembly (Black & McKay, 2017), and attributed to a lack of specific, measurable goals. The Institute would welcome the introduction of targets that are specific, measurable, agreed, realistic and timebound with defined mechanisms in place for monitoring. These should include a clear set of indicators relating to risk reduction as well as indicators relating to service quality and performance and cancer outcomes.

Improving clarity on the resourcing model and priorities for investment

Funding to deliver the strategy recommendations in full is critical. A recent House of Commons Health Funding report, produced by the Northern Ireland Affairs committee, outlined several key areas of concern regarding cancer services including increased demand, waiting times, access to cancer treatment and screening (House of Commons, Northern Ireland Affairs Committee, 2019). The Cancer Strategy Consultation paper clearly outlines that the resourcing model is struggling to keep pace with the service demand, however it is does not outline how resources, once available, will be allocated or prioritised. There is also no detail on how funding will be used to maximum effect, or how the sustainability of the cancer service can be enhanced. It is unclear whether any model of resource allocation will address, specifically, the strategic priorities of cancer prevention and reducing cancer inequalities. In particular, we would welcome a commitment that resourcing of cancer prevention, cancer awareness, cancer literacy and early detection type interventions be prioritised in areas of deprivation.

Enhancing data and research assets to support the strategy and its implementation

The Department's commitment to develop appropriate infrastructure to support a robust research function is welcomed, however there is a lack of detail on what this will look like and accompanying strategic leadership and governance arrangements. High quality data collection and data access is needed to inform decision making, and these will need to be enabled and developed through allocation of resource, infrastructure, and methods to ensure alignment between research and strategic priorities.

The Institute welcomes the acknowledgment in the Cancer Strategy Consultation paper of the substantial expertise provided by the Northern Ireland Cancer Registry (NICR). However, limitations due to the lack of regulations for the 2016 Secondary Use of Data Act and limited access to all current health data systems hamper the potential of the registry. The NICR has over the years developed a significant research and audit portfolio, providing data for health services benchmarked over time, nationally and internationally.

Building on the experience of positive all-island collaboration on cancer data, notably in relation to prostate cancer investigation and treatment and the physical and quality of life impact this has on men (Northern Ireland Cancer Registry, 2021), the strategy should commit to further unlock the potential for collaborations on the island of Ireland. Two national cancer registries currently collect patient-level data on cancer that can be used to inform cancer service planning- the NICR and the National Cancer Registry (NCR) in Ireland. Facilitating data sharing and research collaboration will create economies of scale and efficiencies in developing a greater understanding of cancer and the inequalities that exist on the island of Ireland. The success of collaboration has already been evidenced through the All-Ireland Cancer Consortium, which led to a significant increase in research outputs.

There is a need for a progressive research agenda beyond the clinical aspects of the patient journey, While the Cancer Strategy Consultation paper makes specific commitments to enhance the participation of Northern Ireland patients in clinical trials, a broader view of research and a clear process for prioritisation of research needs is recommended. The patient experience of cancer can be influenced by issues outside the clinical domain. These include practical (work, money, housing, caring responsibilities), relationship, emotional, spiritual and lifestyle concerns (Snowden, et al., 2015). Research on the holistic patient experience with cancer in Northern Ireland would be welcomed. For example, a randomised controlled trial has been conducted in Scotland and England to evaluate the impact of holistic needs assessments in outpatient cancer care (Snowden, et al., 2015).

Driving better understanding of underlying causes of low cancer survival in Northern Ireland

While the low survival rates from cancer in the UK, including Northern Ireland, are acknowledged in the Cancer Strategy Consultation paper, there appears to be a lack of clarity on the most salient intervention points in the Northern Ireland strategic response. The strategy highlights International Cancer Benchmarking Partnership research showing improvements in cancer survival across all seven high-income countries from 1995-2014 but notes that the UK demonstrated the lowest 5-year net survival in a range of cancers, with the exception of oesophageal cancer in Denmark and ovarian cancer in Ireland. Between 1999 and 2007 Northern Ireland has lower survival rates when compared to the European average, particularly for colon, ovary, kidney, stomach, and lung cancers (De Angelis, et al., 2014). However, this data is somewhat out of date, and it is unclear why this disparity may exist. ICBP (2021) has some evidence to suggest that early diagnosis and access to optimal treatment are likely to play a role in survival variation. They note that the UK has later stage diagnosis in comparison to other countries, particularly for lung and colorectal cancer, which may contribute to lower survival and that awareness of increasing cancer risk with age is

lower. They also note that barriers to symptomatic presentation are higher, with patients being particularly concerned with wasting medical professionals' time. Furthermore, across jurisdictions there is a correlation between readiness of primary care to investigate or refer to secondary care and cancer survival. The strategy could commit to a programme of research to better understand the underlying reasons for poorer cancer survival to inform prioritisation and an action plan to enhance cancer outcomes.

Mapping the interface between the cancer strategy and the integrated care system

The focus on co-production in the development of the strategy is welcomed, however there is little detail on how this will be sustained through strategy implementation. The proposed health service reform with an Integrated Care System (ICS) describes a shift of care to the local setting, with an emphasis on community engagement and local decision making. Other than recognising the value of collaboration in creating meaningful change, it is unclear from the Cancer Strategy Consultation paper how it will align with health reform through ICS (Department of Health Northern Ireland, 2021). The proposed ICS seeks to rebalance primary and secondary care clinical leadership in oversight of the service reform, reflecting the move away from the hospital setting to community-based care. It would be useful to know if primary care will be represented, and whether there will be representation from public health specialists to provide expertise on population health, prevention of chronic disease and health inequalities.

To support the Health in All Policies approach in practice, the Department may wish to consider making a recommendation for the use of Health Impact Assessment (HIA) in certain circumstances. HIA could be applied to the overall model, or it could be applied at local level when new proposals are being considered. HIA provides a tool for considering the health impacts of proposals (which may originate from the health system or outside the health system, for example in environmental planning, social protection, policing or transport) and modifying them to ensure that the health benefits are maximised, and health equity is addressed. The Institute will shortly publish a suite of updated guidance documents which will provide the direction and tools needed to undertake a HIA. HIA is aligned with the ICS model in that it provides an opportunity to drive inter-sectoral collaboration and values systematic stakeholder engagement to influence decisions which can impact on health at regional, local or community level. Health in All Policies approach focusing on determinants of health across the life-course. Although the framework refers to the importance of working in partnership with sectors outside of health, it provides no formal endorsement of a deeper ‘Health in All Policies’ approach, the strategic importance of which is becoming increasingly recognised in other countries (World Health Organization, 2013).

Deciding on priorities - understanding of unmet needs and an ethical framework

The most significant increases in cancer diagnoses are predicted for cancers with poor survival (pancreas, liver, and female lung cancers). While some individual service measures are proposed in respect of this trend, there is no strategic focus on these cancers within the proposed actions – for example, there are no set targets for

prevention or commitment of resources to drive early detection or prioritise research or service development for these cancers.

The Institute would welcome a strategic focus on cancers with the following characteristics:

- Low survival and little improvement in survival in the last strategy term
- Common in both incidence and mortality
- Wide social inequality pattern
- Significant scope for prevention
- Relatively neglected in terms of research/service development
- Lower level of patient advocacy/voice

The development and articulation of an ethical framework could help with prioritisation and ensure that decision making on resourcing are based on need, best-evidence and equity and not skewed/biased by advocacy by a range of actors including well-meaning patient groups, health professionals or philanthropists. In addition, a more comprehensive ethical framework could assist with decision making on a range of related issues and management of conflicts of interest within cancer prevention and treatment (Stenmarck, Engen, & Strand, 2021).

Lack of clear focus on actions to address health inequalities

The Cancer Strategy Consultation paper recognises inequalities in cancer incidence and outcomes in Northern Ireland. However, there is a lack of clarity on the strategic approach to reducing inequalities and the priority actions which might be taken in terms of investment, workforce, research, monitoring or community engagement. With this in mind, we would welcome a strategic commitment to engage a 'Task and Finish' group to develop recommendations to reduce inequalities in cancer in Northern Ireland to complement the main Strategy.

It is well established that those living with social and economic disadvantage are more likely to experience poorer health outcomes, have reduced access to health care services and have a lower life expectancy and this is also true for cancer patients. According to Cancer Research UK (2020), at every step of the pathway, the most deprived populations have higher risk, worse experiences and poorer outcomes than the least deprived.

For example, the National Cancer Control Programme (Ireland) conducted a National Lung Cancer Awareness Survey in 2019 (Ipsos MRBI, 2020). A total of 1,250 interviews were conducted nationally, of which 251 were in Dublin 7, 9 and 11 - areas with relatively high incidence of lung cancer compared to the national average. The study found that people living in Dublin areas, which have higher levels of deprivation, reported delaying contacting their GP with potential lung cancer symptoms (nationally 47% of people surveyed would contact their GP as soon as they noticed symptoms, compared to just 12% people surveyed in the Dublin areas), more likely to not want to know if they had cancer (32% in the Dublin areas would not want to know if they had cancer, compared to 14% people nationally) and more likely to have a fatalistic attitude to cancer- with some older participants believing they were beyond help (47% of people in the Dublin areas believed cancer was a death sentence, compared to 30% nationally).

The standardised death rate from cancer in under 75-year-olds is around twice as high in most deprived areas compared to least deprived areas (198 deaths per 100,000 compared with 115 deaths per 100,000 respectively). The standardised cancer incidence rate per 100,000 population if 22% higher in the most deprived areas compared with the least deprived areas (690 per 100,000 compared with 565 per 100,000 respectively). Although lung cancer incidence rose in Northern Ireland overall, the inequality gap remained unchanged. Aggregated data for the period 2012 to 2018, showed that incidence rates from lung cancer were 164% higher in the most deprived areas compared with the least deprived areas (141 per 100,00 compared with 54 per 100,000 respectively) (Carson, 2021).

Cancer Research UK (2020) evidence on the impact of socioeconomic status on cancer incidence and prevalence, diagnosis, treatment, and outcomes across the four UK nations concludes that:

- There are more than 30,000 extra cases of cancer attributable to socio-economic deprivation across the UK.
- The largest differences between the most and least deprived populations are seen in smoking-related cancers, with lung and laryngeal cancer incidence around 3 times higher for the most deprived in England.
- Populations with higher deprivation have higher prevalence of cancer risk factors, are less aware of symptoms of cancer and report more barriers to seeking help.
- More deprived populations are diagnosed at a later stage for some cancers (Lyratzopoulos, et al., 2013).
- Participation in screening programmes is lower among more deprived communities. The likelihood of presenting through an Emergency Presentation route is 50% higher for people in the most deprived populations compared to the least deprived with the risk increasing with every deprivation quintile.
- People from more deprived populations report worse experiences of care and experience inequalities in treatment options. There is evidence that cancer treatment may vary between more and less deprived people with similar patient and disease characteristics, but the reasons for this are not clear. A study in England showed that for lung, oesophageal, stomach and pancreatic cancers, the most deprived patients received different treatments for late-stage disease compared to the least deprived, even after accounting for patient characteristics such as age, sex, ethnicity, and comorbidities. More deprived patients were around 20% less likely to receive chemotherapy, or chemotherapy and radiotherapy combined, compared with the least deprived.
- More deprived groups have worse cancer survival compared to the least deprived, with no improvement in the deprivation gap for survival.

Inequalities in cancer outcomes in Northern Ireland are likely to be compounded by the effects of the COVID-19 pandemic, with vulnerable subgroups of the population more negatively affected. Hamilton et al (2021) undertook an analysis of 3,561 pathology samples indicating a cancer diagnosis in people of all ages in Northern Ireland. Between 1 March and 12 September 2020 there was a 23% reduction in cancer diagnoses compared to the same time period in the preceding three years. Pathological diagnoses of lung, prostate and gynaecological malignancies remained well below pre-pandemic levels. Males, and younger/middle-aged adults, particularly the 50–59-year-old patient group, lagged behind other population demographic groups

in terms of returning to expected numbers of pathological cancer diagnoses. The study authors recognise that socioeconomic status may also be contributing to the observed inequalities and could be included in future research.

Health literacy and communication

The Institute would welcome further commitments to enhance cancer literacy and enhance clarity of communication, both at population level and within the health service setting, and combat misinformation. While these issues overlap with the health inequalities agenda, they are also salient to other population groups with lower literacy and digital literacy, such as older people and women and people who do not have English as their first language. The topic is also salient to the ongoing challenges in clear communication on cancer risk, countering the deliberate attempts by commercial actors to minimise perceived risk associated with their products (e.g., alcohol, tobacco) and the anti-vaccination movement, as relevant to HPV and cervical cancer.

The valid concern of overburdening the health service in Northern Ireland is evident throughout the strategy. Ensuring the service can cope with increased demand is important, and in that way the preventative piece is even more crucial to help reduce the incidence of cancer in Northern Ireland. However, caution needs to be taken with the narrative that is used. Research has shown there are barriers to seeking medical help which are more pronounced in deprived groups, including fear of wasting a medical professional's time or overburdening the NHS (Cancer Research UK, 2020). Therefore, it is important that the strategy does not perpetuate those barriers and instead encourages individuals to seek help when they are concerned.

Public awareness and public health messaging regarding cancer are crucial elements of the strategy, and research on how to best communicate health messages in the local setting would be welcomed. For example, a qualitative study in Ireland (Saab, et al., 2020) explored strategies to promote early detection of lung cancer among at-risk individuals living in high-incidence areas. The study found that participants believed that there was insufficient information regarding lung cancer and recommended promoting lung cancer awareness at a young rather than old age. Participants favoured public health messages that followed the 'SWIFT' acronym: Simple, clear, and honest; Worded positively; Incorporating a shock element; Featuring a celebrity, healthcare professional, or survivor; and Targeted (SWIFT).

Low health literacy is associated with poor health outcomes, including poorer health status, lack of knowledge about medical conditions and related care, lack of engagement with health care providers, lower understanding/misunderstanding of medical information, mortality, and poorer use of preventive health services, poorer self-reported health, and increased hospitalisations, and higher health care costs (Jayasinghe, et al., 2016). There is evidence of low awareness of some cancer risk factors in Ireland; a national survey on lung cancer awareness (Ipsos MRBI, 2020) found that only a small proportion of respondents identified air pollution (13%) drinking alcohol (10%) or obesity/overweight (3%) as risk factors for the disease. People who are socioeconomically disadvantaged have consistently worse experiences at the point of diagnosis, i.e., test results not explained in a way they can fully understand; not having all the information needed about a diagnosis; and less frequently receiving written information about the type of cancer they had in a format or language right for them (Macmillan Cancer Support, 2019).

The strategy outlines the importance of sensitive and timely communication with patients, as well as recognising the challenges which exist when communicating with certain patient groups, such as children, their siblings, and patients with a learning disability or dementia. A qualitative study in Ireland focused on individuals at high risk for lung cancer and aimed to understand awareness and help-seeking for early signs and symptoms (Saab, et al., 2021). The study found that several barriers to help-seeking existed, including a presumption that their GP would hold a negative attitude towards smokers, symptom misappraisal, fear, denial, use of self-help measures, being inherently a non-help seeker, and machoism and stoicism among men. The study highlights the importance of an acting on both intrinsic barriers to help-seeking, deeply rooted in concepts of individual responsibility, self-efficacy, and gender roles as well as the engagement interface in primary care.

We welcome the commitment in the strategy to ensure that all health care professionals who are expected to carry out sensitive communication complete an advanced communication skills training programme. This is an important aspect of cancer care which should be prioritised, and we would particularly welcome efforts to create a service that welcomes, respects and partners with smokers on risk reduction. It has been acknowledged that there are ongoing issues with releasing staff to attend training and having adequate trainers to deliver the training across the service. Adequate resourcing of this training will be central to its success in terms of facilitating staff to attend and ensuring sufficient trainers are in place. In April 2016, Public Health England, NHS England, and the Local Government Association made a commitment to support population-level behaviour change and improve the health of local populations by encouraging staff to make ‘healthy conversations’ part of everyday practice, known as the Making Every Contact Count (MECC) approach; this initiative is a step forward in reducing ill health that results from lifestyle choices and behaviours. Future policy should be aimed at making ‘healthier choices easier choices’ and could include changes in legislation and fiscal measures.

Financial management and cancer survival

The strategy states that benefits advice services, hardship grants to patients and financial guidance are a vital means of supporting people facing the financial hardships caused by cancer. It is acknowledged that whilst services are currently available in all trusts, these are provided and predominantly funded on an annual basis by voluntary sector organisations with no agreed recurrent funding streams. The Institute recommends that an assessment is undertaken to determine the extent of financial support required and how resources are distributed to those most in need. The requirement for practical and financial support is likely to grow as the number of people diagnosed with cancer is predicted to increase and so future planning should take account of this. As voluntary sector organisations have come under greater financial strain during the pandemic, public funding sources should be explored as part of a long-term plan to provide financial support for cancer patients.

In addition to the physical and emotional impact of a cancer diagnosis, for many there is the financial burden of long-term absence from work as well as costs associated with travelling to and attending hospital appointments. A report by Macmillan has shown that four out of five people with cancer are, on average, £570 a month worse off because of their diagnosis. Of 1,600 cancer patients surveyed, a third (33%) had

stopped work either permanently or temporarily, while a further 8% had been forced to reduce their hours or take unpaid leave. It also found that six in seven (85%) people living with cancer face a myriad of increased costs as a direct result of their diagnosis. These range from paying for travel to and from hospital to increased energy bills due to feeling the cold more. The report also found that of those who experienced a financial impact of their cancer diagnosis, 61% said it had negatively affected their quality of life. Within this group, 52% reported feeling anxious of stressed and 43% said it had a detrimental effect on their overall health (Macmillan Cancer Support, 2017).

Recommendations:

- Review the strategic direction to ensure that cancer prevention and cancer services receive an equal level of attention within any final strategy. The Institute recommends that the Department considers cancer prevention through the lens of the 'life-course approach'.
- Consider actions to ensure that the final cancer strategy maintains a leadership role in progressing an ambitious and co-ordinated cancer prevention agenda rather than an observational role. For example, a collaborative approach in Northern Ireland, like the Irish Cancer Prevention Network, may facilitate all-Ireland working in this area. This could also lead to further collaboration with UK partners and assist with public facing messaging given the overlap in the social marketing space between both Islands
- Research to understand the underlying reasons why Northern Ireland may have poorer cancer survival than other regions in Europe would be welcomed to inform strategy development and implementation, particularly if resources need to be prioritised.
- Provide detail on resource allocation, prioritisation of funding, and timeline for strategy implementation
- Review the strategic direction to incorporate a focus on high quality data and research, and collaboration of cancer registry data on the island of Ireland to promote international co-operation and knowledge sharing. A research prioritisation exercise may assist with developing a progressive research agenda.
- Ensure that the strategy aligns with the proposed Integrated Care System model. Consider application of Health Impact Assessment to the whole strategy or to new proposals considered at a local level.
- Consider developing an ethical framework for selection of priority cancers and for prioritising cancer service development.
- Develop a strategic focus and defined action plan to reduce health inequalities, which may also address inequalities associated with priority cancers
- Enhance the strategic approach to health literacy and communication taking account of the current context for information, misinformation, and the digital divide
- Invest in improving engagement skills among healthcare professionals particularly with regards to welcoming, respecting and supporting smokers and other substance users.
- Consider exploring the extent of financial support required to meet the diverse needs of those living with cancer, and how resources are distributed equitably

6. Preventing Cancer

The Cancer Strategy consultation document sets out key information about preventing cancer in Northern Ireland from page 14 - 30 with a number of key recommendations contained in Appendix 1 page 123.

Do you agree that these recommendations will reduce the number of preventable cancers in NI? Please provide details for your answer.

The previous section responding on strategic direction presents our views on the framing and importance of prevention within the Cancer Strategy Consultation paper. These recommendations are re-iterated in part here, along with some additional considerations on prioritisation within the cancer prevention agenda.

The scope for cancer prevention is recognised, but progress on risk reduction at population level across the world has been slow and challenging. While Northern Ireland has made progress on reducing the occurrence of smoking, alcohol consumption and some improvements in physical activity, the pace of change has been small, and the health gains have compounded inequalities in some cases rather than reduced them. In parallel, recent decades have seen large increases in obesity and diabetes, and limited progress on improving the quality of diets in Northern Ireland (Department of Health Northern Ireland, 2021).

The Institute offer some general recommendations on the cancer prevention strand of the Cancer Strategy Consultation paper, and then provide more specific recommendations relevant to each cancer risk factor.

<u>Recommendations:</u>

- Review the strategic direction to ensure that cancer prevention and cancer services receive an equal level of attention within any final strategy
- Consider actions to ensure that the final cancer strategy maintains a leadership role in progressing an ambitious and co-ordinated cancer prevention agenda rather than an observational role
- Incorporate a population-wide approach to prevention whilst exemplifying the proportionate universalism principle, ensuring provision for all, with focussed additional resource for those most at risk/ most in need.
- Use policy and legislative levers to reduce risk factors for cancer through upstream actions that create supportive conditions and environments that make healthy choices easier
- Develop a core indicator set relating to cancer risk reduction, create an open access dashboard and incorporate periodic reporting as part of a wider suite of policy-level indicators
- Conduct research to understand people's attitudes and beliefs on cancer risk and return from risk reduction. For example, through periodic survey data.
- Support the development of cancer risk awareness campaigns and combat misinformation on cancer risk
- Provide transparent timelines for strategies on smoking, obesity, and skin cancer, including a target for NI to reach a 'smoke-free' future

Tobacco use

While the Cancer Strategy Consultation paper acknowledges the importance of tobacco use in cancer prevention, there is an unspecified interface between the design and delivery of tobacco control strategies and the cancer prevention component of the final cancer strategy.

The Institute conducted an evidence review and stakeholder engagement project as part of the mid-term review of the Tobacco Strategy in Northern Ireland (Rodriguez, 2020). Stakeholders viewed the following as the three most challenging areas in relation to tobacco control strategy:

(I) Clarity around the role of e-cigarettes
(II) Stasis on progressive legislation
(III)Reach of the 'Stop Smoking' service to target groups

The evidence review highlighted that systems which support a range of health and social care professionals to systematically identify smoking patients and provide brief intervention and signposting are effective. Interventions delivered by oral health professionals in the dental or community setting are effective in increasing smoking cessation and may be worth expanding. System-level interventions, such as electronic reminders in the clinical setting, led to improved documentation of smoking status, provision of counselling and referral to smoking cessation services. The existing focus in the tobacco control strategy on integration of stop smoking approaches across a range of services including chronic disease management is strongly supported by evidence. The IPH evidence review points to potentially exploring the feasibility of expansion to both substance misuse and HIV/AIDS health and social service settings. Smoking cessation interventions prior to surgery are effective. This evidence supports the case for investment and development of the service and comparing practice and outcomes with other services operating across the UK and Ireland. Review level evidence concludes that investments in training and skills deliver results, particularly in the primary care setting. This evidence supports the case for ongoing investment and development of training and a comparison of practice and outcomes with training schemes operating across the UK and Ireland.

<u>Recommendations:</u>

- Articulate a clear ambition for the reduction of tobacco-related cancers in Northern Ireland setting a target to reduce them by 2031, and including monitoring of this target within a mid-term review of strategy implementation
- Commit to developing better information on the risk reduction from stopping smoking. A review of response to a public awareness campaign run by the Public Health Agency found that among the minority that changed their behaviour, the most common response was to reduce the number of cigarettes smoked rather than make a quit attempt. Together with dual use of tobacco and e-cigarettes and the growth of 'occasional' smokers, these groups may be falsely reassured on the level of risk reduction for cancer.
- Commit to include data on smoking status, screening/ brief intervention, referral, and engagement on all cancer patient records with integration of indicators onto the national cancer registry

- Commit to periodic reporting on the extent of exposure to second-hand smoke at population level and for vulnerable populations within the cancer strategy prevention group of indicators
- Develop a support package for people with cancer to help their families and associates secure a smoke-free environments in their homes and in their place of work
- Commit to the development of bespoke stop smoking services for oncology patients based on best practice (UCD are currently conducting a study on this, but the results are not yet available)
- Commit to include data on cancer status on all records of patients engaging with statutory stop smoking services
- Produce a report which models cancer incidence for different smoking prevalence and tobacco control scenarios in Northern Ireland
- Express explicit support within the Cancer Strategy for the Ministers recent announcement to proceed with legislation to prohibit smoking in cars where children are present
- Commit to maintain a watching brief on evidence relating to risk of cancer and the use of e-cigarettes in terms of both the potential for increasing, and reducing, risk and develop clear guidance for the population, the health and social care service and cancer patients/survivors and their carers
- Provide new structures to better mobilise the voice of patients, carers and cancer service providers on tobacco control issues

Obesity

Overweight and obesity levels in Northern Ireland are high and represent a significant risk for both driving up cancer incidence and reducing cancer survival. A large UK population-based cohort study in 2014 found that body mass index (BMI) is associated with cancer risk with substantial population-level effects (Bhaskaran, et al., 2014). The researchers estimated that a 1 kg/m^2 population-wide increase in BMI would result in 3790 additional annual UK patients developing one of the ten cancers positively associated with BMI.

The Institute would welcome a commitment within the cancer strategy to address obesity in cancer prevention, treatment, and management. The obesogenic environment in which we live makes it more difficult for people to make healthy choices, and so upstream policy action is needed to make the healthy choice the easier choice. The Obesity Health Alliance (2021) recently published a 10-year healthy weight strategy, 'Turning the Tide', which provides recommendations on how the environment within which people live can be more supportive to reduce the risk of obesity. 30 recommendations were made which included regulatory measures across advertising and marketing, food reformulations and accessibility and fiscal levers. No obesity strategy has been successful to date, and this report suggests that this may be due to the overreliance in previous policy on individual behaviour rather than population-wide measures. Evidence is emerging from Netherlands and Australia to support the whole systems approach to obesity which maps action to the local system and epitomises 'Health in All Policies.' Government policies have a key role in influencing the food environment, food system and behaviour change which can be understood through the NOURISHING framework developed by World Cancer Research Fund International (Roberto, et al., 2015). The Institute welcomes the

development of an obesity prevention strategy in Northern Ireland and suggests that the new cancer strategy articulate the need for a strong commitment to obesity prevention in government policy.

Obesity is not always recognised by the public as a risk factor for cancer. For example, a study of women offered breast screening in Australia found that women with obesity were generally not aware they were at elevated risk of breast cancer and were less likely to attend screening. The reluctance of some women to attend was linked to poor body image and prior negative experiences with mammograms relating to their weight. Conversely, providers perceived few issues in screening beyond equipment limitations and health and safety issues. The stigma associated with obesity has also been shown to play a role in healthcare-seeking delays. For example, a study in the United States found BMI to be significantly and directly related to appraisal delay in symptomatic patients who were subsequently diagnosed with colorectal cancer .

Barriers have also been found with cervical screening and may help to explain the higher cervical cancer mortality seen in obese white women. A systematic review reported obese women to be less likely to report being screened for cervical cancer than their lean counterparts (Maruthur, Bolen, Brancati, & Clark, 2009). Barriers may be 'intrinsic' and include negative body image, embarrassment, avoidance of unwanted weight loss advice, or may be physician-related including technical difficulties such as inadequate equipment and difficulty performing examinations (Ferrante, et al., 2010).

Overall, obesity has a discernible relationship with cancer development and can pose barriers to accessing cancer services.

<u>Recommendations:</u>

- Develop modelling for cancer risk reduction from different scenarios of obesity prevalence up to 2031
- Articulate a clear ambition for the reduction of obesity-related cancers in Northern Ireland seeking to reduce them by 2031
- Commit to monitor outcomes for patients with obesity in terms of accessibility of screening, diagnostics, treatment, and patient experience with an initial focus on women's gynaecological and breast cancers
- Research the perceptions of cancer care providers on how obesity may influence decision making on risk and benefit from cancer-directed surgery, radiation, and other cancer therapies
- Conduct an obesity-specific cancer service needs assessment (patients and service providers) to better understand how the cancer service can meet the needs of patients with obesity
- Ensure that cancer prevention forms a component of the obesity model of care, clinical guidelines on the management of obesity and diabetes
- Support the development of skills within the cancer service on how to engage and support people with obesity

Physical activity

The Institute supports the recognition of physical activity in primary and secondary prevention as outlined in the Cancer Strategy Consultation paper and welcome its inclusion in the section on supporting people with cancer to live well. The National Cancer Strategy in Ireland (Healthy Ireland, Department of Health, National Patient Safety Office, 2017) highlights the need for a population approach supported by policy and legislative measures to support population-wide primary and secondary prevention of cancer, and signposts to the National Physical Activity Plan. The Cancer Strategy Consultation paper does not refer to local physical activity action plans in Northern Ireland or overlap actions within the 'Sport and Physical Activity Strategy for Northern Ireland' (Department for Communities, 2021) under development by the Department for Communities.

Sedentary patterns of behaviour are associated with cancer incidence and detrimental to mortality. There is strong evidence that being physically active decreases the risk of cancers of the colon, breast (post menopause) and endometrium. Undertaking physical activity at a vigorous intensity decreases the risk of pre and postmenopausal cancer (World Cancer Research Fund, 2018). WHO Physical Activity Strategy concludes that physical activity confers benefits for incident site-specific cancers which includes bladder, breast, colon, endometrial, oesophageal adenocarcinoma, gastric, and renal cancers (World Health Organization, 2020).

The Institute would welcome a commitment to resource the further development of a comprehensive programme of physical supports for people with a cancer diagnosis and cancer survivors, building on the work of the Macmillan Move More Northern Ireland (MMNI) physical activity referral programme in partnership with Macmillan Cancer Support (Macmillan Cancer Support, 2018) and the eleven district councils across Northern Ireland (Brown, et al., 2021). Physical activity is a vital component of primary and secondary prevention, and as such requires strategic support and resource to support it. For example, physical activity after treatment for cancer can reduce the impact of side effects on physical and mental health (including fatigue, weight changes, anxiety, and depression) (Macmillan Cancer Support, 2011). Evidence also highlights the reduced risk of death from breast and prostate cancer in older adults (Cunningham, O'Sullivan, Caserotti, & Tully, 2020) and a reduction in the recurrence for breast and bowel cancer in those who achieve sufficient levels of physical activity (Macmillan Cancer Support, 2011). A developing evidence base recognises regular physical activity/exercise as an effective supportive care intervention which can induce many physiological and psychosocial benefits, including include improved tolerance to cancer treatment-related toxicities, improved disease outcomes and better quality of life throughout survivorship (Campbell, et al., 2019). A developing evidence base recognises regular physical activity/exercise as an effective supportive care intervention which can induce many physiological and psychosocial benefits, including include improved tolerance to cancer treatment-related toxicities, improved disease outcomes and better quality of life throughout survivorship (Campbell, et al., 2019).

<u>Recommendations:</u>

- Propose the development of physical activity supports for people with cancer through a partnership programme with the forthcoming physical activity strategy

as well as supporting a population-wide approach to prevention and incorporate increasing physical activity levels into the strategy
- Take a health in all policies approach, for example through cross-sectoral working with the Department of Communities on the new Strategy for Sport and Physical Activity.
- Increase capacity by commissioning physical activity programmes for people with a cancer diagnosis and cancer survivors, in addition to community and voluntary sector provision

Climate change and air pollution

The Institute welcomes the call to address environmental pollution in the Cancer Strategy Consultation paper and the recognition of the potential for cancer risk reduction from implementation of the Department of Agriculture, Environment and Rural Affairs with the development of a Clean Air Strategy. However, the Institute suggests that there is an opportunity in this strategy to firmly address the environmental risk factors for cancer, including air pollution and the climate change agenda.

The International Agency for Research on Cancer (IARC) (2013) classified outdoor air pollution as carcinogenic to humans in 2013. The Lancet Commission on pollution and health found that all forms of pollution cause 43% of lung cancer deaths. Climate change worsens acute episodes of air pollution and leads to what is a called a 'climate penalty', as global warming leads to conditions that are more conducive to air pollution. The negative impacts of climate change are not restricted to air pollution and can be seen across the cancer control continuum- from increasing exposure to cancer risk factors (UV radiation, air pollution, infections), changing risk behaviours (in relation to diet, physical activity, and sun protection) and disruption to health systems responsible for detection, diagnosis, and treatment. Therefore, part of the prevention piece must be a strategic, cross-government approach to tackling climate change. The World Health Organization Regional Office for Europe identified three policy priority areas to protect health from climate change in the EU (Lancet Countdown on Health and Climate Change; European Environment Agency, 2021):

-Integrating health into policies for climate change adaptation and mitigation in other sectors

-Integrating climate change into policies and action for public health

-Increasing awareness of and intelligence on climate change and health

By adopting this approach, there may be more opportunity to deliver adaptation and mitigation interventions that maximise health benefits across all sectors. Climate change legislation is going through the Northern Ireland Assembly at present and it could be useful to include modelling of health effects of climate change bill as a strategic objective in the cancer strategy.

<u>Recommendations:</u>

- Make formal recognition within the strategy of the 'health dividend' in terms of reduced cancer incidence from a cross-government approach to climate change mitigation and the reduction of air pollution
- Consider including modelling of health/cancer reduction effects of the climate change bill as a strategic objective of the cancer strategy

Alcohol

Patterns of alcohol consumption in Northern Ireland also represent a significant risk with alcohol-specific deaths in Northern Ireland now the highest in the UK. Analysis conducted by the Institute of Public Health in Ireland (unpublished) suggests that hospital admissions of people with a diagnosis of alcohol-related liver disease has quadrupled in the last 20 years.

Recommendations:

- Make formal recognition of the modelled estimates for reduced cancer incidence and health service use associated with introduction of minimum unit pricing (Angus, et al., 2014).
- Commit to review the effectiveness and feasibility of including cancer warnings on alcohol labelling on an all-island basis, in line with measures proposed in Ireland's Public Health Alcohol Act
- Develop modelling for cancer risk reduction from different scenarios of alcohol consumption up to 2031
- Articulate a clear ambition for the reduction of alcohol-related cancers in Northern Ireland and set a target for reduction by 2031
- Consider actions needed to support early detection of liver cancer among the rising proportion of the population with alcohol-related liver disease

Oral health

The risk of developing oral cancer, including oropharyngeal cancer, oral cavity and lip cancer, is associated with poor oral health even when adjusted for other factors including alcohol consumption and tobacco (Department of Health and Social Care; the Welsh Government; the Department of Health Northern Ireland; Public Health England; NHS England; NHS Improvement, 2021). Health behaviours including attending regular dental appointments and daily toothbrushing are associated with a reduced risk of oral cancers. Despite this there is no oral health strategy in Northern Ireland, creating a real challenge for both policy coherence and system capacity to reduce the risk of oral cancers, enhance early detection and improve cancer survival. Other risk factors for oral cancer include tobacco and alcohol consumption, and when both are consumed the risk increases exponentially. Human Papilloma Virus (HPV) and excessive exposure to UV light are also risk factors for oral cancer. Reduction of these risk factors does not sit with dental health services alone, however there is an opportunity during a dental appointment to provide health promotion advice. The Department may wish to collaborate with dental colleagues in Northern Ireland to

ensure the workforce are trained in behaviour change and health promotion to encourage patients to reduce their risk factors for oral cancer.

Recommendations:

- Commit to develop a cancer specific component to any future oral health strategy in Northern Ireland
- Strengthen health promotion activity to reduce risk factors for oral cancer through collaboration and training with the dental health service

7. Diagnosing and Treating Cancer

The Cancer Strategy consultation document sets out key information about improving outcomes for people living with cancer in Northern Ireland from page 31 -76 with a number of key recommendations contained in Appendix 1 page 123.

Do you agree that these recommendations will improve outcomes for people living with cancer? Please provide details for your answer.

The primary focus of our response is based on cancer prevention. However, in this section we have provided some additional content that may be helpful from a sociological and health equity perspective (rather than a clinical or service development perspective).

Focus on earlier diagnosis

The Institute welcome the focus on earlier diagnosis in the Cancer Strategy Consultation paper. Diagnosing cancer early, before it has grown or spread to other parts of the body is one of the most important ways to increase survival. Lung cancer, for example, ranks first among invasive cancer deaths in Ireland, with a five-year relative survival rate of 17.9%. Earlier diagnosis can be linked to improved survival- for example, in the United Kingdom (UK), the five-year relative survival rate for early-stage lung cancer is 57% in comparison to 3% for patients diagnosed at an advanced stage (Saab, et al., 2021).

Opportunities for enhancing access to cancer diagnostics and services, particularly for vulnerable groups

There is a need for improved access and reduction of barriers to cancer services. Barriers may exist at an individual level, for example, psychological, financial, or practical barriers. For example, in a national survey on lung cancer awareness in Ireland (Ipsos MRBI, 2020), the most common reasons behind a reluctance to see a doctor were concerns about wasting the doctor's time (14%), worrying about what the doctor might find (30%), being too busy (23%) and being too worried about the cost of seeing the doctor (17%). This was the case despite 98% of respondents agreeing that going to the doctor as quickly as possible after noticing a symptom of cancer could increase the chances of surviving.

Barriers can also be at a system level which can lead to inequalities in cancer care. The European Cancer Organisation's Inequality Network produced a report in 2020 to tackle inequalities in cancer care . According to the report, these inequalities relate to geography, ethnicity, gender, including sexual and gender minorities, disability, and socioeconomic factors. We have provided some comments in relation to several of these, as well as issues relating to cancer workforce, health service reform and technological advances.

Gender

Disparities in cancer incidence, experience and outcomes between men and women should be acknowledged in the strategy. While some of these disparities relate to differences in biology, many are also related to gendered factors and norms influencing health behaviours, help-seeking, and compliance with proposed treatment.

European age-standardised incidence rates for many non-sex specific cancers (colorectal, lung, bladder, and stomach) are higher for males than for females (Clarke, et al., 2013). Furthermore, mortality rates for these cancers are significantly higher in males than females (Clarke, et al., 2013). To improve the outcomes of males living with cancer, there is a need to tackle the gender inequalities which affect screening, presentation, stage at diagnosis and access to treatment and clinical trials (Aapro, et al., 2020). Policymakers and practitioners require a better understanding of the factors underpinning gender-based cancer inequalities in order to intervene appropriately to address these inequalities (Clarke, et al., 2013).

Although lesbian, gay, transgender, queer or questioning (LGBTQ+) individuals have higher rates of several viral-related cancers, they access healthcare services less than other people due a fear of discrimination and have lower uptake of cervical screening programmes due to misconceptions about risk factors (Government Equalities Office, 2018). A recent study in collaboration with The Royal College Radiologists, Association of Cancer Physicians and Royal College of Physicians identified low rates of self-perceived knowledge by UK oncologists relating to the specific cancer care needs of sexual and gender minority (SGM) patients (Berner, et al., 2020). Three-quarters felt that they would like further training in this area and two-thirds thought that the cancer care needs of SGM patients should be mandatory within the postgraduate oncology curriculum.

The Institute recommends the inclusion of gender mainstreaming in the cancer strategy. This is defined as *'the process of assessing the implications for women, men, and gender diverse people of any planned action within a health system, including legislation, policies, programmes, or service delivery, in all technical areas and at all levels'* (United Nations Economic and Social Council, 1997). This engagement must go beyond the presentation of data by gender and instead recognise the deeper role of gender in determining health and the interaction with healthcare services.

Geography

Individuals living in rural areas in Northern Ireland have greater difficulties accessing cancer care compared with those living in urban areas due to distance from treatment sites and poorly developed road networks (Black & McKay, 2017). Although the

Regional Cancer Framework has acknowledged the inequalities faced by people living in rural areas, a clear plan is needed in which actions aimed at improving access to cancer services for these people are outlined (Department of Health Northern Ireland, 2008).

Ethnicity

An individual's ethnicity affects their risk for several types of cancer . Furthermore, it plays a role all along the care pathway, with ethnicity-related differences in screening uptake and routes to diagnosis, as well as access to treatment and survivorship. The COVID-19 pandemic illustrated the disparities between ethnicity and health with the disproportionate impact the pandemic has had on people from black, Asian, and minority ethnic (BAME) groups (Public Health England, 2020). People identifying as members of BAME groups are more likely to live in deprived areas which is associated with higher risk of cancer and are also more likely to have been born abroad which means they may face additional barriers to health services due to cultural and language differences.

Factors such as language can be a significant barrier to people from BAME communities accessing health information and services and can negatively impact on outcomes (Macmillan Cancer Support, 2014). The Public Health Agency published a Good Practice Guide, aimed at promoting health and wellbeing in BAME groups (Public Health Agency, 2010). However, the Institute would support a strategy that aims to reduce disparities specifically in cancer care that exist due to ethnicity.

Disability

Individuals with disabilities face many barriers to accessing cancer services such as a lack of preparation and physical accessibility within healthcare settings, as well as a lack of consideration for disability-related needs . The Institute would welcome the implementation of measures to address barriers to accessing cancer services for people with disabilities.

Healthcare reform and technological advances

There is evidence to suggest major healthcare reforms and technological advances may be behind the uniform improvements to cancer survival seen across the seven countries (Arnold, et al., 2019). Rectal cancer survival, for example, has increased across all seven countries and this has been attributed to improvement in surgical techniques, new radiotherapy guidelines and improved diagnosis and staging with new technologies.

There is an opportunity with the proposed Integrated Care System reform for strategic and political leadership to drive the new cancer strategy. The Institute would encourage the Department to ensure that the cancer strategy and proposed ICS are aligned and work together harmoniously, and to capitalise on this time of transformational change in the Northern Ireland Health and Social Care. There have been examples of this internationally; for example, Denmark have had substantial improvements in cancer survival, which may be in part due to the 2007 national

healthcare reform when several changes were made to the cancer service. Cancer became regarded as an 'acute life-threatening disease', cancer specific pathways for diagnosis and treatment were accelerated, large investments in radiology made and hospital waiting times reduced (Arnold, et al., 2019). The Danish Cancer Patient Pathways were developed using a 'consensus-seeking model' and involved cooperation between health professionals, bureaucrats, and politicians in implementation, which may have contributed to the success of the implementation (Probst, 2012). The Institute would encourage the Department to ensure that the cancer strategy and proposed ICS are aligned and work together harmoniously, and to capitalise on this time of transformational change in the Northern Ireland Health and Social Care.

The Institute welcomes the commitment to the development of diagnostic hubs. These have been established elsewhere in the UK and Ireland for rapid access to the diagnostic pathway, and so applying learning from evaluations of these services would be useful to inform the design and implementation.

Sustainable workforce development

The Institute welcomes the focus on sustainable workforce development in the Cancer Strategy Consultation paper. An independent report from Cancer Research UK (2019) highlighted several issues facing cancer services in Northern Ireland, including delayed diagnosis and workforce shortages, particularly in diagnostic staff across clinical radiology, diagnostic radiotherapy, endoscopy and cellular pathology. They make several recommendations including the development of a cancer workforce plan and need for funding to support this.

The urgency of the need for funding to implement a regional workforce plan is well communicated in the Cancer Strategy Consultation paper, however the piece that requires more information is how the current workforce will be supported in the meantime. The Institute would welcome information on specific measures that will be taken to ensure that staff are supported while the workforce plan is developed and that they are involvement and consulted with in the development process. The workplace setting is considered one of the most important determinants of health, and so there is an opportunity to lead by example by investing in the health and wellbeing of its workforce. The Marmot Review lists several key components of a positive work environment, including 'having the ability to participate in organisation decision making'. The Nuffield Trust research report provided evidence-based recommendations on how to best support health and social care staff in the NHS, particularly at times of change such as developing new models of care (Imison, 2016). These recommendations include workforce planning and training, safe governance and regulatory arrangements, clear communication on workforce related issues from sector regulators, research on workforce redesign and the dissemination of good practice examples.

<u>Recommendations:</u>

- Improve accessibility of cancer services, particularly amongst vulnerable groups who may experience additional barriers to care

- Enhance cancer workforce, and maximise impact from health service reform and technological advances

8. Supporting people to live well and die well

The Cancer Strategy consultation document sets out key information about person centred care in Northern Ireland from page 77 - 107 with a number of key recommendations contained in Appendix 1 page 123.

Do you agree that these recommendations will deliver person centred care? Please provide details for your answer.

Need for strategic plan for holistic support for people with cancer and those who support them

The Institute agree with the overall aim communicated in the Cancer Strategy Consultation paper- to commit to a person-centred approach that considers the broad range of areas that a person with cancer may need support with- from financial concerns, caring and work responsibilities to emotional and relationship issues. This approach is welcomed, as is the consideration made to support those people who support the person with cancer including family, carers and staff.

The Northern Ireland Cancer Patient Experience Survey (Quality Health, 2019) and Prue et al. (2021) aimed to understand experiences of care and identify areas for improvement. The need for improvement to supporting patients into survivorship, the need to improve primary care provision for cancer patients and the burden and fatigue of overcrowded cancer clinics were headline findings in the qualitative findings. A need to improve awareness and accessibility of additional voluntary support services in the future was also identified (i.e. Macmillan Move More, Financial info, Macmillan Information and Support Services).

The Institute notes that the Cancer Strategy Consultation paper refers to several interventions, including the Macmillan Recovery Package and use of a Holistic Needs Assessment, but there is no detail on the strategic oversight mechanisms or governance arrangements that will be required for implementation, and there is no detail on how the support strand of the strategy will be evaluated to ensure that it is meeting the needs of those who is aims to support. There is also no recommendation made to support family, carers, workforce and others who support people with cancer.

People with cancer may also have other long-term conditions that increase the pressures they face, or may be vulnerable due to deprivation, marginalisation, or other equity issues. There is a need for this strategy to effectively support people to manage the disease and the impact it has upon their lives, as well as those who support people with cancer.

Mental health

The Cancer Strategy for England (Independent Cancer Taskforce, 2015) outlines a psychological model of care called the “Depression Care for People with Cancer”,

which was found to substantially reduce depression and improve quality of life when compared with usual care (Sharpe, et al., 2014). The National Cancer Strategy in Ireland (Healthy Ireland, Department of Health, National Patient Safety Office, 2017) includes a model of hospital-community psycho-oncology and psycho-social care. The aim of this model is to appropriately meet the needs of all patients whilst ensuring the most efficient use of resources.

In contrast, this Cancer Strategy Consultation paper does not outline any models of care for identifying and managing the mental health needs of patients. The Institute acknowledges that there is a lack of awareness of psycho-oncology services, and access to these services remains a challenge. The Institute would therefore, welcome the development and implementation of such a model, as well as clear care pathways for the priority groups mentioned and for people with existing chronic mental illness or dementia. The Institute would welcome a clear plan outlining how the strategy will integrate and enhance existing community and voluntary psychological support services, social services and allied health professionals to best support patients with cancer.

Recommendations:

- Outline how the strategy will improve the support provided to people with cancer and their support networks, including governance structures, implementation plan and evaluation methodologies
- Consider the design and implementation of a psychological model of care as well as clear care pathways to best support patients with cancer
- Enhance support available for secondary prevention services, such as exercise schemes in the local community

9. Implementing the strategy

The Cancer Strategy consultation document sets out key information about how to enable the delivery of a Cancer Strategy over the next 10 years. There are also a number of key recommendations contained in Appendix 1 page 123.

Do you agree that these recommendations will enable delivery of the 10 year strategy? Please provide details for your answer.

Unclear roadmap and governance structures for change

Overall, there is a need in the strategy for a clear roadmap and logic model to outline how transformational change to cancer services in Northern Ireland will be achieved. At present the strategy does not include a clear roadmap to outline the actions required for strategy implementation, timeline, prioritisation or reference to change management models to support the process. The Institute suggests that strong leadership, robust governance arrangements and reporting structures would strengthen the implementation of the strategy and provide support during a time of transformational change.

Sharing successes and challenges in strategies implemented on the island of Ireland, across the UK and the European region

Cancer contributes to a substantial burden of disease and strategies have been developed and implemented worldwide, including the recently announced 'Europe's Beating Cancer Plan' (European Commission, 2021) as well as a recently refreshed cancer strategy in Ireland. Northern Ireland has the opportunity to learn from the experiences of other countries in strategy development and implementation.

Recommendations:

- Development of structures to support North South working and co-operation across the UK in the development and implementation of cancer strategy
- Border impact assessment in relation to the design and delivery of cancer services in Northern Ireland and Ireland
- A programme of engagement with European level resources, structures and agencies to support Northern Ireland in strategy implementation and translation of research findings
- A plan to horizon scan for any positive or negative implications for cancer strategy from the UK leaving the EU in terms of relationships with European bodies, regulations, access to services, access to medicines, participation in clinical trials and development of the cancer service workforce

Pandemic preparedness

The COVID-19 pandemic has disrupted cancer activity levels across the care pathway. For example, evidence from NHS England shows that GP referrals for suspected cancer, GP referrals and appointments, outpatient appointments and diagnoses were all negatively impacted particularly during the first wave of the pandemic. The number of cancers diagnosed following an emergency presentation increased sharply in July 2020, which suggests that patients did not access services until their symptoms had worsened (Davies, 2021). There needs to be a focus on pandemic preparedness; by harnessing learning from COVID-19 and preparing for the next pandemic, steps can be taken to prevent this happening again in the future.

Research has shown that for some patients, the fear of Covid-19 outweighed the need to seek medical attention. Furthermore, the messaging around not overburdening the health service during the pandemic may also have resulted in some patients delaying their presentation with symptoms. An editorial in the Lancet cited a study which estimated that 45% of those with potential cancer symptoms did not contact their doctor during the UK's first wave of the pandemic (March-August 2020) for the reasons outlined above (The Lancet Oncology, 2021). The same paper suggests that a spike in late cancer presentations and diagnoses is anticipated, making some previously curable tumours more difficult to treat and, unfortunately, further excess deaths unavoidable. There are also concerns that changes to lifestyle, such as unhealthy dietary patterns and reduced physical activity due to lockdowns, may lead to an increase in obesity-related cancers in the future.

The Northern Ireland Cancer Registry reported a 10% reduction in the number of patients with a pathological sample indicating cancer between 1 March 2020 and 17

April 2021 compared with the same time period between 2017-2019. Based upon the monthly trend in patients with pathology samples indicating cancer, there was an estimated shortfall of 1,040 patients during Mar-20 to Mar-21 compared to the expected number. Some of these "missing" patients may have a clinical only diagnosis (e.g. as a result of an emergency hospital admission) (Northern Ireland Cancer Registry, 2021).

The Institute recognises that HSCNI has faced significant challenges in recent years which were further exacerbated by the pandemic. It is likely that health services will continue to face challenges posed by other public health threats such as the burden of chronic disease, worsening mental health and climate change to name a few. Forward planning and a strong focus on resilience in the design and implementation of cancer services is vital and would welcome a recognition of 'system resilience' in the new cancer strategy.

WHO refer to system resilience as 'the capacity of a system to absorb, adapt, anticipate and transform when exposed to external threats – and/or to forecast shocks that bring about new challenges and opportunities – and still retain control over its remit and pursuit of its primary objectives and functions' (World Health Organization, 2017). The COVID-19 pandemic exposed the fragility of health systems in Northern Ireland and across the world. Evidence is emerging and we are yet to fully understand the true impact of the pandemic on service delivery and health outcomes. It will be important to examine the evidence in terms of service uptake and service user experience to inform future service planning which must prioritise narrowing the health inequality gap.

The new strategy is an opportunity for Northern Ireland to strengthen the resilience of its health system to 'better tackle current and future patterns of ill health; create conditions for the protection and promotion of health and the reduction of health inequities; and increase preparedness in dealing with unexpected risks for population health' (World Health Organization, 2017). There are different areas in which resilience could be enhanced, and some examples include strengthening primary care capacity, investing in workforce development, planning and support, and integrating strong leadership and governance structures.

10. Please use the space below share any additional information you feel is relevant to this consultation. We are particularly interested in responses that relate (but not limited) to the EQIA and Rural Needs elements of this consultation.

Nil to add

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