A Cancer Strategy for Northern Ireland 2022-2032

Department of Health
An Roinn Sláinte
Männystrie O Poustie
www.health-ni.gov.uk

Minister's Foreword

My vision is to ensure that everyone in Northern Ireland, wherever they live, has equitable and timely access to the most effective, evidence-based referral, diagnosis, treatment, support and person-centred cancer care.

Over time, cancer impacts on the lives of all of us. The number of cancer cases diagnosed in Northern Ireland has increased 54% over the past 25 years and is projected to double by 2040. While there have been many advances in the diagnosis, treatment and care of people over recent years we know that, with many more people surviving cancer combined with a rapidly ageing population, our current system is unsustainable.

I believe we can do better for people of all ages, including children, teenagers and young adults, who have cancer. Transformational change is needed if we are to provide evidence-based, high-quality care for all those who need it in the future.

Cancer services were challenged before the pandemic and there continues to be significant capacity and workforce challenges across a range of areas. There is a need to move forward urgently to implement the actions outlined in this Strategy to rebuild and transform our services in the short, medium and longer term. The Cancer Strategy affords us the opportunity to look forward 10 years to identify and implement what will really make a difference for people living with cancer.

Reducing health inequalities is integral to the implementation of this Strategy. Social deprivation and health inequalities are a major contributory factor in the development of the majority of cancers. This means that there are potentially avoidable variations in outcomes, patient experience and survival across Northern Ireland. Tackling inequalities goes far beyond the remit of my Department and will require a concerted, coordinated focus across Government Departments. Improving cancer services for the people of Northern Ireland must be a major priority for the whole Executive in the years ahead.

At the heart of the many successes of cancer services is the hard work and dedication of our staff, in every band and role, who are delivering care at higher levels than ever before. In addition to maintaining oncology services throughout the pandemic, many staff from a wide range of professions have been involved in the development of this Strategy.

The successful delivery of this Strategy will require collaboration. It will involve maintaining and building on the many successful developments over the past years in response to the pandemic and learning from what could have been done better. Collaboration between HSC organisations, across sectors and with patients, families and carers, will be a key enabler to effecting meaningful change.

This Strategy has been co-produced with people living with cancer and staff providing treatment and care under the leadership of Professor Charlotte McArdle and Ivan McMinn MBE. As we move towards implementation, we will ensure that this collaborative working continues.

This 10-year Strategy is ambitious. Significant recurrent funding is therefore required if we are to deliver these recommendations to improve diagnosis, treatment and care for all those who need it now and in the years ahead.

Robin Swann
Minister of Health

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Developing a Cancer Strategy for Northern Ireland

Why we need a Cancer Strategy

Cancer is a common condition. In Northern Ireland one in two people born since 1960 will be diagnosed with some form of cancer in their lifetime. Survival has improved for many cancers over recent years and now over half of people will live ten years or longer following diagnosis and treatment. This is largely due to earlier detection, improvements in treatments and changes in exposure to risk factors. The number of people diagnosed is, however, expected to continue to rise, largely due to our ageing population.

More than 26 people in Northern Ireland are diagnosed with cancer every day, and almost 10,000 people are diagnosed with cancer annually. The number of cancer cases diagnosed increased by 54% over the past 25 years and is projected to double by 2040 (45% for males and 58% for females). Large increases are predicted for many cancers with poor survival rates including pancreatic and liver cancers and lung cancer in females with only stomach and cervical cancer numbers projected to decrease.

This brings considerable challenges to health services in meeting the ever-growing demand for diagnostic services, screening programmes, treatment, follow-up surveillance, supportive and palliative care. Increased demands will be felt across the entire health and social care system as many people diagnosed with cancer are also living with multiple other long-term conditions.

Although cancer survival in Northern Ireland has improved over the years, it still lags behind other comparable countries both in Europe and internationally. The International Cancer Benchmarking Project (ICBP) Module 1 report showed cancer survival in Northern Ireland to be behind other parts of the UK, Australia, Canada, Denmark, the Republic of Ireland, New Zealand and Norway. Northern Ireland consistently ranked between 8th and 10th out of the 12 jurisdictions involved.

Recently published ICBP Module 21 evidence shows that the UK as a whole had the lowest one- and five-year survival rates from 2010–2014 for four of the seven cancer types reviewed.

Cancer has accounted for over 20% of all deaths in Northern Ireland every year since 1987. In 2018, the most recent year for which detailed statistics are available, cancer was the leading cause of death – accounting for 28% of all deaths. Unsurprisingly, death rates from cancer are usually higher among those aged 85+ than any other age group among both men and women.[1]

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[1] Macmillan (2021) ‘Statistics Fact Sheet’ https://www.macmillan.org.uk/_images/cancer-statistics-factsheet_tcm9-260514.pdf

England, Scotland and Wales and the Republic of Ireland have, in recent years, produced new cancer strategies for their respective jurisdictions designed to further improve the outcomes for people affected by cancer.

These strategies have all identified new approaches to service planning and delivery as well as prevention.

The New Decade, New Approach Agreement gave a commitment that the Executive would develop a new Cancer Strategy by the end of December 2020; however, this deadline had to be pushed back due to the COVID-19 pandemic.

The Cancer Strategy affords us the opportunity to look forward 10 years to identify and implement what will really make a difference for cancer patients in Northern Ireland. This will require a comprehensive approach to prioritisation – making rapid change early where possible and laying the groundwork for truly revolutionary evidence-based interventions where we know this could transform outcomes.

Strategy Development

The development of the Strategy has been based on co-production which has brought together people with lived experience of cancer and healthcare professionals from across all the Health and Social Care Trusts (HSC), the Public Health Agency (PHA), Health and Social Care Board (HSCB), Primary Care, policy makers and cancer charities. The Strategy aims to place Northern Ireland at the forefront of world-class cancer prevention, treatment and patient experience.

A Steering Group was established to oversee the development, supported by seven sub-groups: prevention; diagnosis and screening; treatment; care and support; living well; palliative and end of life care, children and young people.

The aims of the Strategy are threefold:

- to reduce the number of people diagnosed with preventable cancers;
- to improve survival; and
- to improve the experience of people diagnosed with cancer.

This process is illustrated in Driver Diagram [2] – Developing a Strategy in Appendix 6.

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[2] 'Progress in cancer survival, mortality, and incidence in seven high-income countries 1995–2014 (ICBP SURVMARK-2): A population-based study', The Lancet Oncology, 2019.

Cancer in Northern Ireland

Cancer services were challenged before the pandemic with unacceptable waiting times and significant capacity and workforce challenges across a range of areas. COVID-19 has led to a worsening waiting times position, resulting in considerable anxiety for patients and staff.

A Cancer Recovery Plan, Building Back; Rebuilding Better was published on 24 June 2021 to address the immediate issues in adult cancer services with the aim of getting us to a place where services are stronger than before.

Over this time period, the focus will be on stabilising existing cancer services, supporting and growing the workforce and improving data collection and analysis to enable the implementation of longer-term actions. In parallel there is an urgent and compelling need to innovate, develop, test and adopt new ways of working using technology.

Key Aims of Building Back; Rebuilding Better

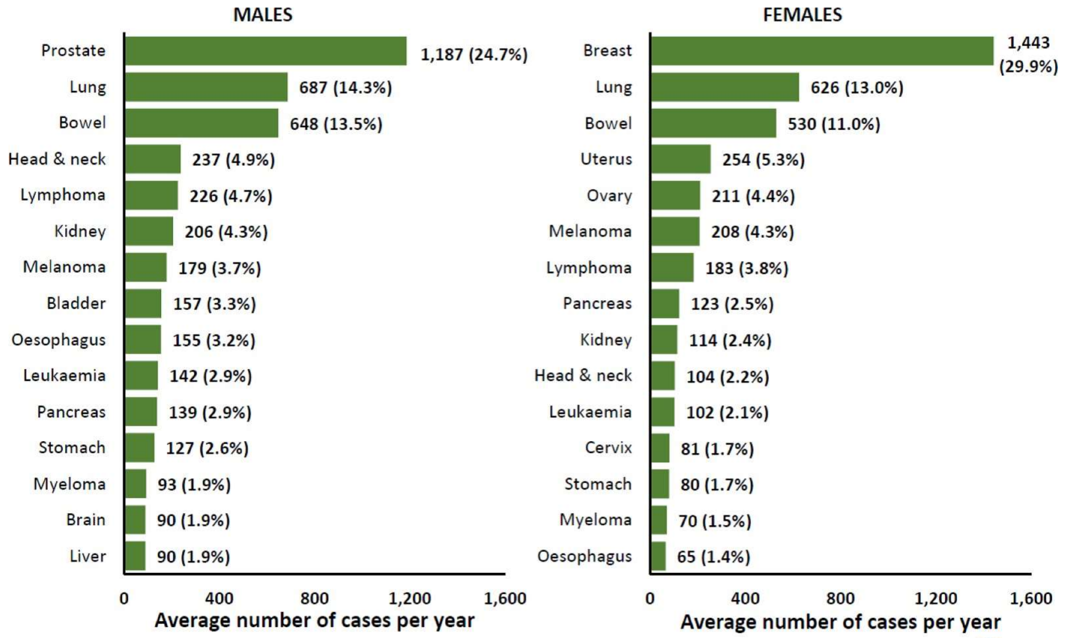
- To adopt a regional approach for Northern Ireland, where appropriate, to ensure patients receive equitable access to diagnostics, care, treatment and support.
- To create smoother and more efficient patient pathways from initial referral, through diagnosis and treatment encompassing the appropriate care and support during and after treatment with the aim of improving cancer waiting times and patient outcomes and patient experience.
- To invest in cancer services and enable new, more sustainable, models of care that will be resilient to potential future surges of COVID-19 and to the projected increase in cases of cancer.
- To learn from the impact of COVID-19 on cancer services and the wider HSC and adopt successful innovations for the future.

The aims of the Recovery Plan are subsumed in the Strategy. Therefore going forward, implementation of the Recovery Plan will be through the implementation of the Strategy.

Cases

In 2018, cancer was diagnosed in 13,452 people from Northern Ireland; 3,823 of these were Non-Melanoma Skin Cancer (NMSC), a disease that is easily treated and causes few deaths but which uses health service resources and also causes a lot of concern and trauma to patients. This Strategy takes account of these conditions but focuses on the more serious, almost 10,000 per year, cancers which are a major cause of cancer deaths. The most common cancer in men (excluding NMSC) was prostate (1,187 cases per year, 25%), and in women was breast cancer (1,443 cases per year, 30%). Lung (1,313 cases per year) and colorectal cancers (1,178 cases per year) were common in both genders (see Figure 2.) Blood cancers (lymphoma, leukaemia and myeloma) combined account for around 800 new cancer cases per year and collectively make blood cancer the 5th most common cancer in Northern Ireland.

Figure 1: Average number of cancers diagnosed per year by sex and cancer type: All cancers (ex. NMSC), 2014-2018



Source: Northern Ireland Cancer Registry

The risk of developing cancer increases with age, with two thirds (67%) of cases in men, and over half (58%) in women diagnosed over age 65. This compares to 11% of cases (ex. NMSC) diagnosed in those under 50 years. Those living in socio-economically deprived areas had overall cancer levels 15% higher than the Northern Ireland average, with especially higher rates for lung (70% higher per year), liver, head and neck, cervical and stomach cancers. Those living in higher socio-economic areas had levels 6% lower than the Northern Ireland average overall, but higher levels of prostate cancer and melanoma.

The number of cancer cases diagnosed has increased by 54% over the past 25 years and is projected to double by 2040 (45% for males and 58% for females).

This projected rise is due primarily to population ageing. Large increases are predicted for the cancers with poor survival (pancreas, liver and, especially in women, lung cancers), with only stomach and cervical cancer numbers projected to decrease. Cancers which are largely preventable and predicted to increase include melanoma and lung cancer.

Every year in Northern Ireland, around 60 children under 16 years of age and 80 teenagers and young adults aged 16–24 years are diagnosed with cancer. While there is variation year to year, these numbers have remained stable over the past 20 years.

The most common types of cancer diagnosed in the 0–15 age group are blood cancers and brain tumours.

Teenagers and Young Adults refers to people aged 16 up to their 25th birthday. The numbers of cancers diagnosed are low and the most common cancers in this age group are lymphoma and leukaemia, testicular, ovarian, brain and colorectal cancers.

Deaths

Cancer was the largest cause of death in Northern Ireland during 2018, with 2,326 male (30%) and 2,122 female (26%) deaths per year. The most common causes of cancer death among men were lung (554, 24%), prostate (276, 12%) and bowel (232, 10%), and among women were lung (469, 22%), breast (314, 15%) and bowel (207, 10%).

Prevalence

The number of people living at the end of 2018 after a diagnosis of cancer (prevalence) is estimated at 97,807 (including 37,894 with NMSC) with 12% of these diagnosed in the previous year. The most common cancer types prevalent (ex. NMSC) in men were prostate (10,938) and bowel (4,713), with breast (16,462) and bowel (4,048) the most common among female survivors.

By 2033, the number of cancer survivors in the population is projected to increase by over 40%. Many patients will be cured, others will live for many years with cancer as a long-term condition and for others the disease will progress.

Although many more people will be cured from their cancer, not all continue to live well and for many, the late effects and consequences of treatment will present life-long problems. Cardiac problems due to some chemotherapy drugs, bowel problems post-pelvic radiotherapy and osteoporosis due to hormonal therapies and prolonged use of steroids are some of the many ongoing problems survivors have to deal with.

Survival

Cancer survival is a key measure of the effectiveness of cancer services, reflecting preventive initiatives such as vaccinations (HPV), screening, early detection, access to timely diagnostics and rapid and effective treatment by specialists. Stage at diagnosis is important. Currently 48% of pancreatic, 44% of lung and a fifth of cancers overall are diagnosed at a late stage when the treatment options are limited and survival is poor.

Five-year survival varies considerably by cancer site. In addition to poor survival for lung cancer (12%), survival is very low for other tobacco-related cancers (e.g. pancreatic, stomach and oesophageal cancers). Changes in tobacco use could have the greatest impact on cancer incidence and survival. Cancer survival rates in Northern Ireland, like the rest of the UK, fall short when compared internationally. While year-on-year improvements in survival have been documented, the COVID-19 pandemic is likely to reduce survival.

Improvements in treatment seen in the past five decades mean that around 80% of children 0–16 years diagnosed with cancer in the UK will survive their cancer for at least five years. This means there is a growing population of children and young adults who have experienced cancer and treatment as children. Most will require ongoing follow up and support and some will require this for life.

Health Inequalities

It is well established that those living with social and economic disadvantage are more likely to experience poorer health outcomes, have reduced access to healthcare services and have a lower life expectancy and this is also true for cancer patients. According to Cancer Research UK (2020),[3] at every step of the pathway, the most deprived populations have higher risk, worse experiences and poorer outcomes than the least deprived.

Inequalities in cancer outcomes are likely to be compounded by the effects of the COVID-19 pandemic with vulnerable subgroups of the population more negatively affected.

Inequalities in health arise because of inequalities in the conditions in which people are born, grow, live, work and age. These conditions influence the ability of individuals, families and communities to take control over their lives and choices, and whether they are enabled and supported to lead long, healthy, active lives.

Health inequalities are associated with lower symptom awareness, later presentation and lower uptake of services including screening. Inequality across Northern Ireland means there are potentially avoidable variations in

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[3] Cancer Research UK (2020). ‘Cancer in the UK 2020: Socio-economic deprivation, s.l: Cancer Research UK’ https://www.cancerresearchuk.org/sites/default/files/cancer_inequalities_in_the_uk.pdf

outcomes, patient experience and survival. The majority of cancer types have much higher incidence in more deprived areas. There is strong evidence linking risk factors, which are more common in areas of deprivation with higher incidence of cancer, including smoking, obesity and poor diet. Addressing health inequalities cannot be achieved by the recommendations of this Strategy alone and will require a concerted cross-departmental approach.

Low levels of health literacy are associated with poorer access to health services, poorer communication with healthcare professionals, lower adherence to treatment and poorer self-management of health conditions. Better health literacy could therefore contribute to reducing health inequalities and improve healthcare efficiency.

Major strides have been made in the development of relationships with many community and voluntary sector organisations as a result of the pandemic. We need to learn from the COVID-19 experience and continue engagement with lesser heard communities, including ethnic minority groups, people with learning disabilities, communication difficulties and those for whom English is not their first language, to ensure equality of access to cancer services across the pathway and to information and support services.

Theme 1: Preventing Cancer

Making Life Better

From the evidence, it is clear that reducing the number of preventable cancers in Northern Ireland will require a concerted focus across government. Policy responsibility for a range of areas including air pollution, radon, environmental exposure and use of chemicals lies within other government Departments.

Making Life Better (MLB) is the overarching strategic framework for public health through which the Executive committed to creating the conditions for individuals, families and communities to take greater control over their lives, and be enabled and supported to lead healthy lives.

The All Department's Officials Group (ADOG) is a key part of the structures for co-ordinating the implementation of MLB. Its key function is to bring together senior officials from all Departments and to inform and support the Executive's Ministerial Committee for Public Health in carrying out their role of providing strategic leadership and cross-government coherence effectively. ADOG could therefore be used as the mechanism to engage with other Government Departments and Agencies in addressing the wider social determinants of cancer, and ensuring that government policy aligns to prevent cancers developing in the first place.

The proportion of cancer incidence in Northern Ireland attributable to modifiable lifestyle and environmental factors is estimated to be in the 30% to 40% range. A population approach, supported by policy and legislative measures, is required to encourage and support people to live healthier lives and reduce the prevalence of cancer risk factors such as tobacco and alcohol consumption, obesity, lack of physical activity and UV radiation exposure.

Cancers in children are largely driven by growth and development. Thus we see an increase in germ cell tumours in adolescents linked to genital growth, an increase in bone tumours throughout childhood with spurts in adolescence linked to bone growth, peaks in acute lymphatic leukaemia linked to lymphoid tissue growth, and peaks in brain tumours in childhood and adolescence linked to neural growth.

Like other European countries, the number of cancers in Northern Ireland is increasingly driven by an ageing population, changes in exposure to risk factors and improved survival as a result of earlier detection and better treatments. Recommendations for individuals to reduce their risk of developing cancer are outlined in the European Code Against Cancer in Appendix 6.

There is evidence to suggest that the pace of change in reducing the risk factors underpinning these cancers is not sufficient. Ultimately, this highlights the real need to maintain focus on tackling preventable cancers, and the urgency for accelerating change. Although death rates for cancer are falling, the total number of cancer deaths continue to rise due to an increase in the numbers of older people in the age range when the cancer typically occurs. This brings considerable challenges to health services in meeting the demand for care as well as the impact on the individuals affected. Treatment services alone cannot address the burden of cancer care. Prevention must be a key focus of this Strategy as it offers the most long-term, cost-effective approach; however it will take time before the impact can be realised.

By implementing robust prevention strategies not only can we reduce the risk of cancer by up to 40% but also up to 75% of new cases of heart disease, stroke and type 2 diabetes, and significantly reduce the risk of dementia.

Figure 2: Main Known Modifiable Risk Factors

SMOKING

Tobacco is the single greatest modifiable risk factor for cancer prevention.

ENERGY IMBALANCE & DIET

Being active lowers the risk of colon, breast, prostate & endometrial cancers.

Excess weight raises the risk of gallbladder, liver & kidney cancers.

Heavy consumption of processed meats & high GI foods increase the risk of cancer. Low GI foods decrease it.

RADIATION & OCCUPATIONS

UV radiation is the main cause of skin cancer.

Overexposure to radon gas increases the risk of lung cancer.

Some occupations are linked with a higher risk of cancer, eg mining, construction, manufacture.

30-50% of all cancers are PREVENTABLE (World Health Organisation)

INFECTIONS

Papilloma viruses increase the risk of cancers of the cervix, penis, vagina, anus & oropharynx.

Hep B & Hep C increase the risk of liver cancer.

H pylori increases the risk of stomach cancer.

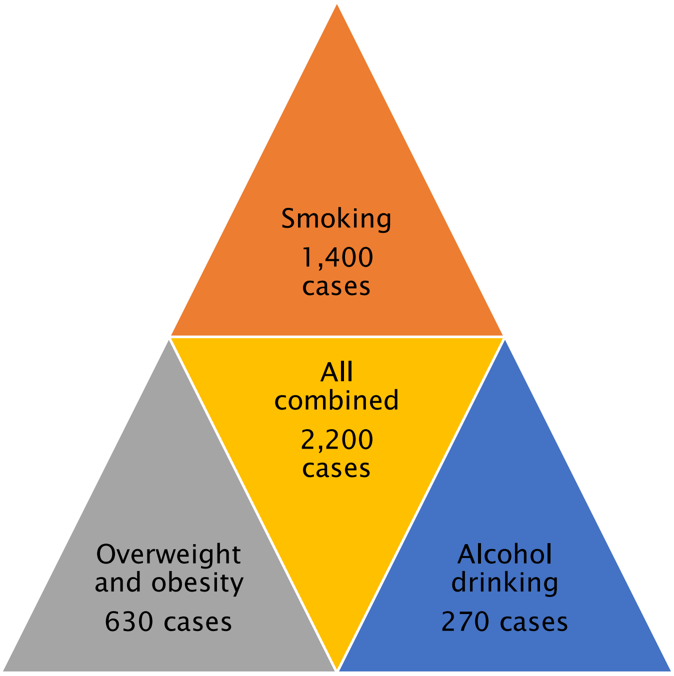
ALCOHOL USE

Heavy alcohol intake is a risk factor for oral cavity, pharynx, larynx, liver, bowel & breast cancers.

ENVIRONMENTAL POLLUTION

Air pollution increases the risk of lung cancer.

Figure 3: Estimation of Preventable Cancer Cases in Northern Ireland



- Nearly 4 in 10 cancer cases could be prevented.
- It can take years for the cancers caused by modifiable risk factors to exhibit. The impact of current / new prevention measures may not be seen in the short term.
- Not all modifiable risk factors have the same impact on cancer.

Smoking, overweight and obesity and alcohol drinking cause around 1,100 cases in men and 1,100 cases in women every year.

Cancer Risk Factors

Smoking

The numbers of new cases of lung cancer are falling as a result of the decrease in smoking prevalence over several decades. Tobacco use, however, continues to be a significant factor in many cancers and cancer deaths. There are over 1,300 cancer deaths per year caused by smoking. It is the main cause of preventable death from cancer in Northern Ireland.

The vast majority of lung cancers and over half of all head and neck cancers (oral cavity, oesophageal, laryngeal and pharyngeal) can be attributed to smoking. Smoking is also a contributory factor in many other cancers including kidney, bladder, liver, pancreas and cervix. Public awareness of the links between smoking and lung cancer are strong but there are low levels of awareness of the wide range of other preventable cancers caused by smoking.

Smoking prevalence has fallen
24% in 2010/11
17% in 2019/20

Obesity

Obesity is responsible for almost 600 cases of cancer each year in Northern Ireland. It is a key contributory factor associated with cancer risk and mortality, including breast, uterus, liver, gall bladder, colorectal and kidney cancers.

Obesity is the second biggest preventable cause of cancer in Northern Ireland.

65% of adults are overweight or obese with around a quarter of children aged 2-15 either overweight (20%) or obese (6%). Trend analysis shows that there are no indications of a decrease in rates of overweight or obesity. There is a low level of understanding amongst the general public of the links between obesity and cancer.

There is no single action that will solve Northern Ireland's high obesity and overweight prevalence; a combination of actions is required to address the food environment and ensure that people are supported to live healthier lives.

People need to be supported to make healthier food choices, removing triggers to purchase unhealthy food, and ultimately reduce prevalence of overweight and obesity. This in turn will lead to fewer obesity-related cancers.

Overweight and obesity rates are rising
62% in 2018/19
65% in 2019/20

Diet and Physical Activity

The importance of lifestyle factors including physical activity, sedentary behaviour and diet, and their association with cancer has been recognised in recent years.

Breastfeeding is the best start for baby and has a protective effect for the mother. Breastfeeding for 12 months reduces the risk of developing breast cancer in the future by over 4%. In 2020, it is encouraging to note that breastfeeding was attempted for around six out of ten births (62.5%) in Northern Ireland, a 5.7% increase from 2015. There is however a deprivation gap with 48% of mothers living in the most deprived areas reporting as attempting to breastfeed compared to 76% from the least deprived areas. Efforts to increase breastfeeding must be supported across a range of programmes both in midwifery units and in the community.

High consumption of processed meats is a major contributory factor to bowel cancer. Conversely a diet high in fruit and vegetables reduces the risk of many cancers including bowel, stomach and oesophagus.

Health Survey data 2017/18 shows that 17% of adults ate processed meats most days of the week. This is an increase from 15% in 2010/11. There is a gender differential with more men than women eating processed meats on most days of the week (23% v 13%) and a deprivation gap between the most and least deprived (26% v 13%).

In 2019/2020, 56% of adults ate less than the recommended five portions of fruit and vegetables per day, down from 68% in 2010/11. The proportion of those eating five or more portions was lower for men and for those living in the most deprived areas.

Sedentary behaviour is associated with a higher risk of many cancers but most notably, colon, endometrial and breast cancer.

Health Survey data for 2016/17 shows that 43% of adults did not meet the recommended levels for physical activity. There is a gender differential with more women than men not meeting the guidelines (48% v 37%) and a deprivation gap between the most and least deprived (55% v 35%).

39% of those living in the most deprived areas reported eating five or more portions of fruit and vegetables compared with 54% of those in the least deprived areas.

Ultraviolet Radiation

Skin cancer is the most common form of cancer in Northern Ireland. Incidence has trebled since the mid-1980s. By 2040, a further 82–149% increase in malignant melanoma cases and a further 99–132% increase in non-melanoma skin cancer cases are predicted.

The main cause of skin cancer is over exposure to UV radiation from the sun or artificial tanning devices. Health survey results (2016/17) indicate that 4% of females and 1% of males currently use sunbeds, and 31% of females and 12% of males have used sunbeds in the past. The number of sunbed premises has more than doubled in 10 years, to 19.6 sunbed businesses per 100,000 population in 2019.

The Health Survey 2016/17 reported that 34% of adults in Northern Ireland never check for any changes in their skin which could indicate skin cancer and 22% reported having had sunburn in the previous year.

Sunbed use poses a specific risk for melanoma, independent of skin type and of solar exposure. Melanoma risk increases with younger age of first sunbed use and with greater lifetime use of sunbeds. Sunbed use has also been associated with increased risk of non-melanoma skin cancers and ocular melanoma (cancer of the eye), especially for those who started artificial tanning at a younger age.

Development of any new version of the skin cancer prevention Strategy should give consideration to including a specific focus on occupational skin cancer. The World Health Organisation (WHO) is expected to introduce a new 1CD-11 code for skin cancer of occupational origin in 2022.

Alcohol

Drinking alcohol causes almost 300 cases of cancer a year in Northern Ireland. Alcohol causes a variety of types of cancer: mouth, upper throat (pharynx), larynx, oesophageal, breast, bowel and liver. These encompass some of the most common cancer types and some of the most difficult to treat. The risk of some of these cancer types is increased even at low levels, e.g. oesophageal, oral cancers and breast cancer, while others are only increased at moderate to heavy consumption, e.g. bowel and liver respectively. When combined with smoking, the risks are increased significantly. Awareness amongst the public of the relationship between alcohol and cancer is low.

There is an opportunity for alcohol consumption to be highlighted as a significant risk factor during the implementation of the new 10-year Substance Use Strategy, ‘Preventing Harm, Empowering Recovery’ launched by Minister Swann in September 2021.

Around 80% of adults 18 and older drink alcohol.

Infections

Several specific infections are implicated in the development of some cancers including H pylori, hepatitis B and C and the human papilloma virus (HPV). H pylori is associated with an increased risk of stomach cancer; however, it is no longer common in the UK and for most people it is successfully treated with antibiotics and will not cause any further problems.

Chronic infections with hepatitis B and C are associated with an increased risk of developing liver cancer. Laboratory confirmed cases of both hepatitis B and C have increased significantly in the past decade. A hepatitis B immunisation programme for young children was introduced in 2017 which will subsequently reduce the risk of developing cancer in the future.

HPV is one of the most common sexually transmitted infections. Infections with HPV cause the vast majority of cervical cancers, most anal cancers and a significant proportion of oropharyngeal, vaginal, vulval and penile cancers. The HPV vaccination programme for both adolescent girls and more recently boys has been very successful in reducing sexually transmitted infections. As a consequence, this will reduce the numbers of these cancers in the future. To date this programme has successfully almost eliminated cervical cancer in women born since 1995.

Men having sex with men, aged under 45 and who are attending genitourinary clinics, can also avail of HPV vaccinations.

Going forward, it is crucial that we maintain the high uptake rates for these vaccination programmes.

In addition, comprehensive sex education and awareness programmes must be developed and implemented to reduce the number of sexually transmitted infections which could lead to the development of a preventable cancer.

Oral Health

Cancer of the oral cavity is on the increase, particularly among our younger population. This includes cancers of the lip, tongue and oropharynx.

Attendance for routine examination and care is an ideal time for ‘opportunistic’ screening. In addition, dentists also have a key role to play in supporting many people having treatment for cancer.

The established risk factors for developing mouth cancer are smoking (or using tobacco in other ways for example chewing tobacco), drinking alcohol and infection with the human papilloma virus (HPV). The risk of developing oral cancer for those who use tobacco and drink alcohol is greater than the sum of the separate risks (i.e. the risk is multiplied not added). Oral cancers caused by HPV tend to affect younger individuals than those associated with alcohol and tobacco.

In 2019, 273 people in Northern Ireland were diagnosed with oral cancer, 182 males and 91 females. The median age at diagnosis was 63 for both males and females. Over the 25 year period from 1993 to 2019, the number of people diagnosed with oral cancer in Northern Ireland has increased by almost 80%.

Unfortunately, the majority of oral cancers in Northern Ireland are diagnosed at stage IV which has a significant impact on survival. Five year survival rate for oral cancer in Northern Ireland is approximately 45% overall but is almost 69% for those diagnosed at stage I and only 24% for those diagnosed at stage IV. Like many other cancers, studies indicate there is a socio-economic gradient with oral cancer – the risk of developing oral cancer is significantly greater among those from deprived communities.

Environmental Pollution and Radon

In 2013, the International Agency for Research on Cancer (IARC) confirmed that outdoor air pollution is a cause of cancer. In Northern Ireland, around 70 cases of cancer each year are caused by exposure to outdoor air pollution.[4] The smallest particles known as PM10 and PM2.5 are linked to lung cancer.

Air pollution in Northern Ireland comes from a variety of sources. Domestic combustion (burning wood and open fires) is one of the biggest sources of PM10 (27%) and PM2.5 (44%) in the UK.[5] Road transport is responsible for 11% both of PM10 and PM2.5 emissions across the UK,[6] of which 27% to 43% is from vehicle exhaust emissions and the remaining is from tyre and brake pad wear.[7]

Radon is a radioactive gas which is naturally produced in the ground from uranium which is present in small quantities in soil and rocks. Most radiation exposure from radon arises from inhaling its short-lived solid radioactive decay products rather that radon itself. Radon is recognised by the International Agency for Research into Cancer (IARC) as a Class 1 carcinogen (IARC, 2012). In the UK, exposure to indoor radon is responsible for an estimated 1,100 lung cancer deaths each year with smokers and ex-smokers at the greatest individual risk. There is currently no strong evidence to link radon exposure to cancers other than lung cancer or to other diseases. The Department of Agriculture, Environment and Rural Affairs and other agencies are contributing to a UK National Radon Action Plan.

Action 1. **Increase public awareness of cancer-related risk factors through specific strategies on tobacco, substance use, skin cancer prevention, and overweight and obesity – including diet and physical exercise.**

Action 2. **Support the development and delivery of strategies to improve public health.**

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[4] Northern Ireland Department of Agriculture, Environment and Rural Affairs (2020) Clean Air Strategy for Northern Ireland – Public Discussion Document (pdf) https://www.daera-ni.gov.uk/sites/default/files/consultations/daera/20.21.066%20Draft%20Clean%20Air%20Strategy%20for%20NI%20-%20Public%20Discussion%20Doc%20Final%20V6.PDF.

[5] UK Department for Environment, Food and Rural Affairs (2020) National Statistics - Emissions of air pollutants in the UK, 1970 to 2018 – Particulate matter (PM10 and PM2.5) ((https://www.gov.uk/government/statistics/emissions-of-air-pollutants/emissions-of-air-pollutants-in-the-uk-particulate-matter-pm10-and-pm25).

[6] UK Department for Environment, Food and Rural Affairs (2020) National Statistics - Emissions of air pollutants in the UK, 1970 to 2018 – Particulate matter (PM10 and PM2.5) (https://www.gov.uk/government/statistics/emissions-of-air-pollutants/emissions-of-air-pollutants-in-the-uk-particulate-matter-pm10-and-pm25).

[7] UK Air Quality Expert Group (2019) Non-Exhaust Emissions from Road Traffic (pdf)

Chemoprevention

Chemoprevention is the use of medication to prevent the development of cancer and is a relatively new approach to cancer prevention. Its use is primarily focused on those known to be at a significantly higher risk of developing cancer, for example those with a strong family history or diagnosis of a pre-malignant or predisposing condition. Guidelines produced by the National Institute for Health and Care Excellence (NICE) for familial breast cancer recommend that women at an increased risk of breast cancer should be offered medication to reduce their risk.

There is also emerging evidence of the protective effect of aspirin in Lynch Syndrome. Going forward, as new evidence emerges, chemoprevention is likely to play a greater role inthe prevention of more cancers.

Action 3. Develop a co-ordinated approach towards chemoprevention in line with NICE recommendations.

Secondary Prevention

There is a long-established evidence base showing that certain behaviours are linked to the development of cancer (smoking, being overweight/obese, drinking at harmful levels, diet and exposure to UV without protection). People who have developed cancers arising from these factors may worry about the cancers returning, and could be at an increased risk of recurrence without behavioural changes. Multiple studies have demonstrated strong evidence for the benefits of physical activity in reducing the risks of both cancer recurrence and death from cancer for a variety of tumour types. It is known from feedback from patients and health professionals that people who have been diagnosed with cancer would like more information, tailored to their individual needs on how to make diet and lifestyle changes.

Trusts must offer advice to all people treated for cancer, tailored to their individual circumstances and risk level, on how to improve their lifestyle. Advice should be relevant to the person being treated could include healthy eating, weight control, physical activity, smoking cessation and alcohol consumption, to help prevent secondary cancers and reduce the risk of recurrence. People treated for cancer should be signposted to local services in their community where they can be supported in making their lifestyle changes.

Action 4. All people diagnosed with cancer must be offered appropriate and targeted information and support to live well.

Theme 2: Diagnosing and Treating Cancer

Diagnosing Cancer

Pathways to Diagnosis

People can receive a cancer diagnosis in a variety of places such as screening centres, GP surgeries, hospital settings including outpatient departments, inpatient wards and emergency departments. Increasingly during the COVID-19 pandemic people received their diagnosis in their own homes by phone. The circumstances under which a person is diagnosed with cancer is strongly associated with their subsequent survival.

The first ever Pathways to a Cancer Diagnosis report for Northern Ireland was published in January 2020.[8] This was a research project between the Health Foundation, Queen's University Belfast (QUB) and Business Support Organisation (BSO) which looked at how and where patients with cancer are diagnosed. It is based on well-established methodology from Public Health England. Information from the Routes-to-Diagnosis in England has helped in the transformation of the cancer patient pathway by focusing attention on awareness raising, early presentation to Primary Care, followed by rapid diagnosis and treatment.

One of the key findings of the work was to highlight the significant proportion of people being diagnosed in the emergency department, the majority of whom are presenting with late stage disease. This includes 28% of blood and lymph cancers, 42% of digestive tract cancers, 27% of upper gastrointestinal tract, 25% of head, neck, brain and eye cancers and 35% of lung cancer. Other key findings were the significant survival differences dependent on the route to diagnosis, with three-year survival highest for screen-detected cancers at 97% compared to three-year survival of 21% for those presenting as an emergency.

It is important that this work is repeated regularly in order to understand how improvements in the system and increased public awareness are impacting on how and where people are presenting, being diagnosed and the stage of disease at diagnosis.

Action 5. Establish routes to diagnosis reporting and analysis on a regular basis to monitor changes to help improve diagnostic pathways and outcomes for patients.

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[8] HSCNI, Pathways to diagnosis, www.hscbusiness.hscni.net/services/3094.htm.

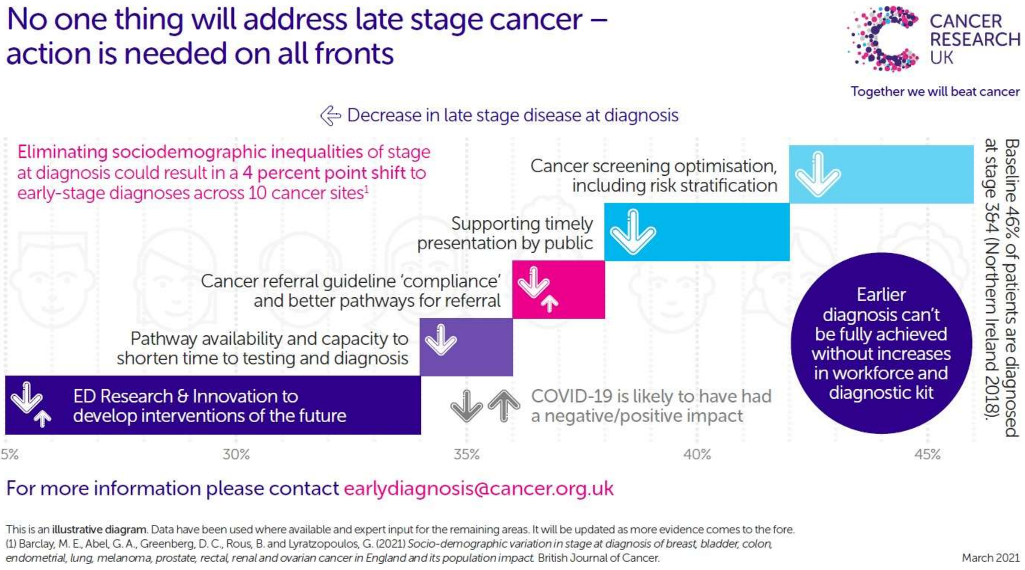
Reducing Late-stage Diagnosis

There is no one thing that will achieve a reduction in late-stage cancer diagnoses; we need to act together across a range of different interventions, and across the diagnostic pathway, in a co-ordinated and considered way.

This includes speedier and more equitable implementation of what we know, and research to identify the innovations and shifts of the future.

This waterfall diagram has been developed by Cancer Research UK and estimates the contribution that acting at different parts of the pathway could contribute to the all cancer stage shift. Originally, it was developed in anticipation of a significant national commitment to early diagnosis in England. In January 2019, the NHS England Long Term Plan outlined an ambition that, by 2028, 75% of cancer patients should be diagnosed at stage I or II. In this iteration of the diagram, we reframe it to focus on reduction in late-stage cancer diagnoses for Northern Ireland. In 2018, 46% of all cancers were diagnosed at stage III or IV (out of those with a known stage at diagnosis.)

Figure 4: Waterfall diagram to highlight early diagnosis need



No one thing will address late stage cancer – action is needed on all fronts

For more information please contact earlydiagnosis@cancer.org.uk

This is an **illustrative diagram**. Data have been used where available and expert input for the remaining areas. It will be updated as more evidence comes to the fore.

(1) Barclay, M. E., Abel, G. A., Greenberg, D. C., Rous, B. and Lyratzopoulos, G. (2021) *Socio-demographic variation in stage at diagnosis of breast, bladder, colon, endometrial, lung, melanoma, prostate, rectal, renal and ovarian cancer in England and its population impact.* British Journal of Cancer.

March 2021

The potential impact of COVID-19 has been reflected in the diagram. We cannot yet be certain of the actual impact of the pandemic but it is reasonable to assume that disruptions to cancer screening, altered patient and health professional behaviour, reduced availability of tests and protracted pathways will have a negative impact which may translate into poorer patient outcomes. The waterfall also highlights the need for significant progress and rapid translation of early detection and diagnosis research, as well as further service improvements, including investment in the workforce, equipment and other infrastructure. It also notes the importance of addressing inequalities in stage at diagnosis.

Raising Awareness

Early diagnosis is a complex, multifaceted topic dependent on a range of factors including public awareness of symptoms, access to primary care, access to diagnostic services, referral guidelines and pathways. People who recognise abnormal or persistent symptoms and seek medical advice are much more likely to have earlier stage disease and have better outcomes.

Raising public awareness on the signs and symptoms of cancer has been proven to be successful elsewhere in the UK. England and Scotland run regular campaigns designed to raise awareness of the signs and symptoms of different types of cancer and to encourage patients to visit their GP if they experience symptoms or notice changes in their body.

The Public Health Agency (PHA) developed a cancer awareness programme for Northern Ireland, Be Cancer Aware, in 2015. It has a dedicated website but, largely due to funding constraints, there have been no media campaigns run since 2016.

There is evidence that people from lower socio-economic groups often have lower recognition of signs and symptoms of cancer. This is likely to be the case for other seldom-heard and harder to reach groups, particularly those from ethnically diverse backgrounds and those with learning disabilities. Awareness raising campaigns must be co-produced and specifically tailored to be more easily understood. Input from health psychologists to support the development of resources and to evaluate the outcomes and subsequent behavioural change should be considered. Consideration must also be given to translation of resources into other languages and to the provision of appropriate resources for those people with sensory impairment and communication difficulties.

Many cancer charities have a focus on promoting awareness and have developed excellent resources in accessible formats. There is much to be gained in combining efforts and working in partnership with community and voluntary sector organisations which often are more successful in reaching minority populations where the need is greatest.

Action 6. Deliver regular, effective, targeted evidence-based ‘Be Cancer Aware’ campaigns harnessing the expertise in the community and voluntary sector.

Screening

Screening programmes are targeted at large groups of the population, the majority of whom will have no symptoms of cancer. Screening offers the opportunity to diagnose many more cancers at a much earlier stage leading to better outcomes for patients. Three programmes currently exist in NI, breast, bowel and cervical. There is, however, considerable variation in the uptake of all three programmes, with poorer uptake strongly associated with social deprivation.

The UK National Screening Committee (UK NSC) makes evidence-based recommendations to UK nations regarding population screening programmes. In the past, Northern Ireland has been slower than other nations to adopt some recommendations made by the UK NSC. Going forward we will address this.

Professor Sir Mike Richards recently published his review of adult screening programmes in England. While most of the recommendations were for England specifically, there are a number of things that should be adopted by devolved screening programmes, including those in Northern Ireland. They should include participation in any new UK screening advisory body, annual publication of routine performance data and quality assurance reports for screening programmes, and high priority given to an integrated approach to increasing uptake and coverage.

Going forward, cancer screening programmes will continue to evolve and new programmes will be developed for people at higher risk.

Bowel Screening

Bowel cancer is the third most prevalent cancer in Northern Ireland and the second leading cause of cancer death. The bowel screening programme is offered to people aged 60–74. The programme detects 8.3% of all bowel cancers. 67% of cancers detected through bowel screening are at an early stage. Removal of early polyps detected through screening can very often prevent cancer from returning or developing any further.

The qFIT test is a new easier to use home test for bowel screening which only needs one sample instead of the current three samples. It has been rolled out in all other UK nations and was introduced in Northern Ireland in January 2021. The first confirmed results from Scotland after their introduction of qFIT showed increased uptake of bowel cancer screening from 55.4% to 63.9%. Importantly, this increased uptake was seen in men, areas of higher deprivation, and in difficult to reach audiences. This increase in uptake means more pre-cancerous changes and cancers are likely to be detected – and at an early stage.

Going forward plans will be developed to reduce sensitivity levels incrementally and to extend the age range in line with these recommendations within an agreed timeframe.

The success of the bowel screening programme is highly dependent on access to timely endoscopy services. There are very significant challenges with the capacity of endoscopy services across all Trusts. These must be addressed as a priority to cope with existing demands and to be able to accommodate reductions in sensitivity levels and widening of age bands in the future. There are other emerging tests being rolled out at pace elsewhere in the UK, for example colon capsule endoscopy. Early adoption of such tests may well be key in terms of developing a sustainable response to the ever increasing demand for endoscopy services.

Breast Screening

Breast screening is the most established cancer screening programme in NI. 29% of breast cancers are diagnosed via the screening programme. Mammography for all women aged 50-70 and registered with a GP is carried out every three years via mobile and static units. It is available for women aged over 70 on request. Trials have begun in England to explore broadening the age range from 47-73. This is likely to have a significant impact for Northern Ireland if it is deemed to be successful. The ongoing success of breast screening services is reliant on responsive symptomatic breast cancer services in all Trust areas.

Cervical Screening

Cervical screening is offered to all people with a cervix aged 25-49 every three years and every five years for those aged 50-64. 24% of cervical cancers are detected via the screening programme.

Samples are taken in a GP surgery and are analysed in a laboratory using a process called cytology. If abnormal cells are detected, the sample is then tested for high-risk Human Papilloma Virus (hr-HPV). hr-HPV is the most common cause of cervical cancer.

In 2016, the National Screening Committee recommended that cervical screening programmes switch to testing for hr-HPV as the primary test. Switching to hr-HPV as the primary test does not require anything different at the point of testing but does require some reconfiguration of laboratory services. In the short term, it is expected to increase referrals for colposcopy investigation. In the longer term, HPV testing is a more accurate test than cytology and will ultimately be more cost-effective by enabling a longer interval between tests. It is intended to implement the change in 2022/23.

Pilot studies on self-sampling are underway across the world and in some parts of the UK. This may improve uptake and become more mainstream.

Lung Screening

There are over 1,300 cases of lung cancer diagnosed in Northern Ireland annually and over 1,000 deaths. Five-year survival is very poor at only 12.1%. 35% of lung cancers are diagnosed via emergency presentation, with almost 70% of those diagnosed at late stage (III or IV). People diagnosed at later stages have fewer treatment options and this leads to the disease having a very poor survival rate. Over half of all diagnoses are in the lowest two deprivation areas; incidence is 70% higher in the most socially economically deprived areas than the average.

The NELSON trial is a Dutch Belgian lung cancer screening trial which has shown a 24% reduction in mortality for men and 33% reduction for women after 10 years of screening.

The UK National Screening Committee (UKNSC) is currently considering the introduction of a targeted lung cancer screening programme for the UK which would identify and test those at higher risk of the disease based on an agreed set of criteria including age and smoking status. It has commissioned an external review of screening for lung cancer in individuals at increased risk and it is expected that the public consultation will be launched in 2022. Those invited for a screening would receive a low dose, non-contrast CT scan, which is better at identifying lung cancer than plain film x-ray.

In October 2016, the UK Lung Cancer Coalition published ‘25 BY 25 – A ten year Strategy to improve lung cancer survival rates’.[9] They recommend that the Public Health Agency should consider evidence from trials for a local pilot for lung cancer screening in Northern Ireland.[10] No pilot currently exists in Northern Ireland.

Action 7. Reduce sensitivity levels and extend the age range for the bowel screening programme.

Action 8. Implement HPV testing in the cervical screening programme.

Action 9. Increase uptake of all cancer screening programmes.

Action 10. Implement all UK National Screening Committee recommendations.

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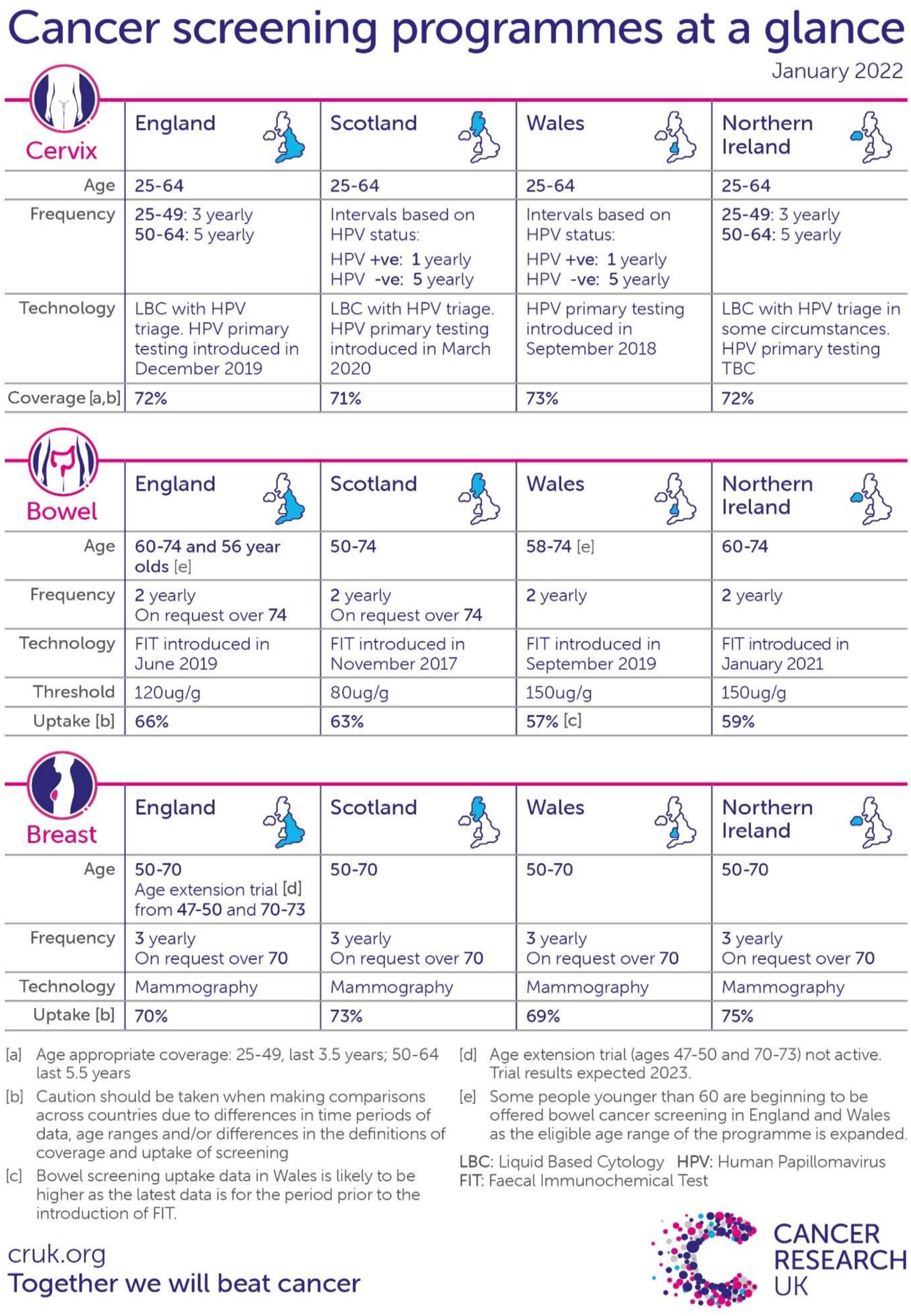
[9] UKLCC, 25 by 25A ten year Strategy to improve lung cancer survival rates, 2016, https://www.uklcc.org.uk/our-reports/october-2016/25-25.

[10] The New England Journal of Medicine (2020) ‘Lung Cancer Screening and Nelson Trial’, N Eng J Med 2020, 382: 2164–2166.

Figure 5: Screening for cancer



Cancer screening programmes at a glance

January 2022

Cervix	England	Scotland	Wales	Northern Ireland
Age	25-64	25-64	25-64	25-64
Frequency	**25-49:** 3 yearly **50-64:** 5 yearly	Intervals based on HPV status: HPV **+ve: 1** yearly HPV **-ve: 5** yearly	Intervals based on HPV status: HPV **+ve: 1** yearly HPV **-ve: 5** yearly	**25-49:** 3 yearly **50-64:** 5 yearly
Technology	LBC with HPV triage. HPV primary testing introduced in December 2019	LBC with HPV triage. HPV primary testing introduced in March 2020	HPV primary testing introduced in September 2018	LBC with HPV triage in some circumstances. HPV primary testing TBC
Coverage [a,b]	**72%**	**71%**	**73%**	**72%**

Bowel	England	Scotland	Wales	Northern Ireland
Age	**60-74 and 56 year olds** [e]	**50-74**	**58-74** [e]	**60-74**
Frequency	**2** yearly On request over **74**	**2** yearly On request over **74**	**2** yearly	**2** yearly
Technology	FIT introduced in June 2019	FIT introduced in November 2017	FIT introduced in September 2019	FIT introduced in January 2021
Threshold	120ug/g	80ug/g	150ug/g	150ug/g
Uptake [b]	**66%**	**63%**	**57%** [c]	**59%**

Breast	England	Scotland	Wales	Northern Ireland
Age	**50-70** Age extension trial [d] from **47-50** and **70-73**	**50-70**	**50-70**	**50-70**
Frequency	**3** yearly On request over **70**	**3** yearly On request over **70**	**3** yearly On request over **70**	**3** yearly On request over **70**
Technology	Mammography	Mammography	Mammography	Mammography
Uptake [b]	**70%**	**73%**	**69%**	**75%**

[a] Age appropriate coverage: 25-49, last 3.5 years; 50-64 last 5.5 years

[b] Caution should be taken when making comparisons across countries due to differences in time periods of data, age ranges and/or differences in the definitions of coverage and uptake of screening

[c] Bowel screening uptake data in Wales is likely to be higher as the latest data is for the period prior to the introduction of FIT.

[d] Age extension trial (ages 47-50 and 70-73) not active. Trial results expected 2023.

[e] Some people younger than 60 are beginning to be offered bowel cancer screening in England and Wales as the eligible age range of the programme is expanded.

LBC: Liquid Based Cytology **HPV**: Human Papillomavirus
FIT: Faecal Immunochemical Test

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CANCER RESEARCH UK

Targeted Surveillance

Significant research developments are happening at present which will bring changes to the organisation and delivery of services so that patients at higher risk of a condition can be ‘targeted’ for additional surveillance so that an early diagnosis of cancer can be made for these conditions.

Many precancerous lesions, if detected, can be adequately treated preventing progression to cancer. Progression from precancerous disease to cancer varies by site and there has been limited research following patients with precancerous conditions on a population basis.

In Northern Ireland, research teams at Queen’s University Belfast have established the following precancerous databases:

- Barrett’s Oesophagus Register – The Northern Ireland Barrett’s Oesophagus Register is one of the largest population-based registers of Barrett’s Oesophagus worldwide
- Colorectal Polyp Register
- Endometrial Hyperplasia Register
- Monoclonal Gammopathy of Undetermined Significance (MGUS)

These databases are enabling researchers to identify clinical and molecular characteristics that predict progression to cancer that can facilitate service planning and healthcare provision. Expansion of the precancerous databases would enable improved patient outcomes.

Action 11. Create surveillance systems for conditions where there is clear evidence regarding the pre-malignant potential of a particular condition to ensure people are not lost to follow up.

Referral Guidance

In 2015, the National Institute for Health and Care Excellence (NICE) launched their newest 'Suspected cancer: recognition and referral NG12' guidance. These are guidelines for GPs when determining whether/how to refer someone with suspected cancer. England and Wales currently use these NG12 guidelines, and Scotland uses their own guidelines, though there are many similarities to NG12. Northern Ireland has not introduced this NICE-recommended cancer referral guidance NG12, and uses guidelines developed by the Northern Ireland Cancer Network, (NICaN) most recently updated in 2019.

The current 2015 NICE version is widely recognised as being limited in its application for children and young people. The Childhood Cancer and Leukaemia Group has worked with NICE to create a NICE-endorsed supplement for Children & Young People which is linked from the NICE NG-12 Tools and Resources page.[11]

NG12 guidance frames how suspected cancer is dealt with by primary care, by organising guidance by symptom and by cancer site and including information on primary care investigations and safety-netting. This design aims to make guidance easier to interpret and utilise. NG12 was developed using a risk threshold where if the risk of symptoms being caused by cancer is above a certain level then action (investigation or referral) is warranted. In 2015, NICE guidance changed, meaning that more people are referred for tests in an attempt to improve early diagnosis, and they now reflect how non-specific and challenging some cancer symptoms are to detect and manage.

There have been concerns that the introduction of NG12 would lead to increased referrals to diagnostic services, creating further pressure on already stretched services.

NG12 guidelines[12] also include a significantly increased level of GP direct access to some diagnostic tests for certain cancer types. This includes plain film x-ray, computerised tomography (CT), Magnetic Resonance Imaging (MRI), non-obstetric ultrasound (NOUS) and endoscopy. GPs in Northern Ireland have a very low level of direct access to diagnostic tests compared to elsewhere, and there is a wide variation across Northern Ireland and by test modality.

Direct access to tests can speed up access to testing, reduce the number of patient appointments and potentially improve timeliness of diagnosis.

Several new diagnostic tests broadly under the heading of 'liquid biopsy' are in development or testing. Liquid biopsy refers to tests of body fluids

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[11] Queen's University Belfast (2018) 'Official Stats 2018' https://www.qub.ac.uk/research-centres/nicr/FileStore/OfficialStats2018/ Factsheets2018/Filetoupload,957488,en.pdf.

[12] NICE, 2015, Suspected Cancer: Recognition and Referral https://www.nice.org.uk/guidance/ng12/resources

including blood, saliva, faeces or urine. One major advantage of tests such as these is that they are much less invasive than a traditional biopsy, for which a sample of a suspected tumour is removed for analysis in the lab, sometimes requiring a general anaesthetic. It is highly likely that one or more of these tests will be approved for use soon.

A liquid biopsy pilot is being undertaken by NHS England. The test claims to be able to diagnose 25 different cancers by checking for molecular changes in cell-free DNA. It is targeted at people aged 50–79 with no symptoms and is designed as a triage test and not a replacement for traditional diagnostic tests. If successful this is likely to be a game changer for the future in helping to diagnose cancers much earlier using less invasive procedures. HSC should monitor development of these tests to be ready to implement them at pace whenever evidence shows their effectiveness.

Targets

Currently Northern Ireland has three measurements for cancer waiting times:

- At least 95% of patients should begin their first treatment for cancer within 62days following an urgent GP referral for suspected cancer
- At least 98% of patients diagnosed with cancer should begin their first definitivetreatment within 31 days of the decision to treat
- All urgent breast cancer referrals should be seen within 14 days

Northern Ireland also measures diagnostic waiting times (75% of patients should wait no longer than nine weeks for a diagnostic test, with no patient waiting longer than 26 weeks). These diagnostic waiting time measures, while they do include cancer tests, can only provide broad information about diagnostics generally.

There is no metric for measuring diagnostic time specifically for cancer, red flags or staging investigations. The 62-day cancer waiting time target is often used as a proxy for cancer diagnostic waiting time, but it actually measures the time from referral to first definitive treatment which is not exclusively diagnostic time, and only applies to those with a red flag referral via a GP. The 62 days include time for patients to have all diagnostic tests required to make their diagnosis of cancer and, while it doesn't track the diagnosis interval exclusively, can provide general information on the performance of cancer diagnostic services. This target was introduced in 2009 but has never been met.

The long-running poor performance against both the 62-day cancer waiting time target and the diagnostic waiting time target would point to a problem with diagnostic services, but the current targets don't allow clear identification of where the key blockages are in the system, and so it has been difficult to identify clear changes that would improve patient diagnostic waiting times.

The current cancer waiting time targets have not been reviewed since they were implemented in 2008. They do not currently apply to recurrent cancers or metastatic disease. Any review of targets must include all people undergoing treatment to ensure the whole cancer pathway is as efficient and responsive as possible.

Wales' new Single Cancer Pathway[13] is unique in that it is the only cancer waiting time measurement which includes all cancer referrals, regardless of source or classification. It includes all suspected cancer referrals from GPs, screening referrals, referrals from emergency departments and other specialty consultants, and combines them all into one single waiting time

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[13] Wales Cancer Network, http://www.walescanet.wales.nhs.uk/single-cancer-pathway

target of 62 days from point of suspicion of cancer to first definitive treatment.

Early diagnosis is extremely relevant to Teenagers and Young Adults who often experience challenges during the pathway to a diagnosis because risks and symptoms are not easily recognised and acted upon.[14] Young people will often navigate through the health system differently to older adults, and this needs consideration to ensure there are effective systems to provide a safety net and ongoing referral.

Consequently this can result in young people presenting later with more advanced disease resulting in the need to provide more "intensive and prolonged therapies, increased toxicities, higher costs to the HSC and families and ultimately poorer outcomes"[15]

We are unlikely to make significant changes to childhood and young adult cancers through prevention approaches and conversely need to focus on awareness campaigns and earlier detection for this age group as a priority. The Childhood Cancer and Leukaemia Group have developed a Child Cancer Smart Early Diagnosis and Awareness Campaign.[16] Together with the existing Head Smart tool[17] for brain tumours, there is the opportunity to raise awareness among healthcare professionals to enable earlier diagnosis.

In general, earlier diagnosis not only significantly increases survival but it is also more cost effective if patients can be treated with less intensive treatments for earlier stage cancers. This is important across all ages and even more so for children and young people.

Action 12. Implement NICE guidance including NG12 and, in the future, the most current NICE referral guidelines.

Action 13. A 28-day standard will be introduced to track the time for all people from first referral for suspected cancer to confirmation of a cancer diagnosis, which includes all diagnostic and staging investigations.

Action 14. Review current targets to ensure equity across the pathway.

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[14] Dommett, R.M., Pring, H., Cargill, J. et al. Achieving a timely diagnosis for teenagers and young adults with cancer: the ACE "too young to get cancer?" study. BMC Cancer 19, 616 (2019).https://doi.org/10.1186/s12885-019-5776-0

[15] Walker, D.A. (2021) 'Helping GPs to diagnose children's cancer', British Journal of General Practise 2021; 71 (705): 151–152.

[16] Walker, D.A. (2021) Helping GPs to diagnose children's cancer British Journal of General Practice 2021; 71 (705): 151- 152 https://bjgp.org/content/71/705/151 https://www.cclg.org.uk/ChildCancerSupport.

[17] HeadSmart – Early Diagnosis of Brain Tumours, (2022),https://www.headsmart.org.uk/.

People with Vague but Worrying Symptoms

Arguably some of the most difficult people to diagnose are those who present with vague but concerning symptoms, sometimes several in combination. Their symptoms are often non-specific and can leave the GP without clear guidance on which specialty to refer these patients to. There is currently no clear pathway for these people and they can often be ‘bounced’ between various consultants,diagnostic tests and general practice in an effort to make a diagnosis. Individuals presenting in this way experience longer times to diagnosis overall and poorer clinical outcomes compared to those with site-specific recognisable symptoms.

“Frequent delays in getting tests done, results back and waiting for information is an unnecessary waste of time and money.”

The concept of diagnostic hubs for patients with vague but worrying symptoms originated with the Accelerate Coordinate Evaluate (ACE) programme inEngland, facilitated by Cancer Research UK (CRUK) and Macmillan based on models developed in Denmark. Analysis of data from five pilot sites demonstrated a cancer diagnosis for 8% of all people referred. A significant proportion of these would be considered rare or hard-to-diagnose. In addition more than a third of patients were diagnosed with other conditions and referred to the appropriate service.

“The issue of being ‘ping-ponged’ back and forth rang bells. I would welcome an all-in-one diagnostic centre. I have been through tests, and nothing found in that region, and then back to the GP to start again.”

England, Wales and Scotland have all adopted versions of this specificpathway for patients with vague butworrying symptoms.

Diagnostic Centres

Currently diagnostic tests are done linearly – people are referred for one test which is reported and reviewed before referral for additional tests. We do not currently have the ability to order tests as a cluster – even if the clinician knows in advance that a certain grouping of tests will be required. This results in people having repeat visits to diagnostic facilities for testing which lengthens their diagnostic interval.

There has been no sustained improvement in cancer or diagnostic waiting times over several years, despite efforts by Trusts and others to increase capacity and access to tests. A new approach is required to improve the diagnostic pathways. If change is not made, waiting times will continue to deteriorate and more people could be diagnosed late, impacting the effectiveness of treatment and even survival.

Diagnostic tests are carried out in a wide range of facilities. In many sites, the equipment for diagnostics is also used for acute and emergency presentations, causing potential scheduling issues. In some areas, radiology and endoscopy are not available on the same site. Diagnostic imaging is performed in all acute hospitals across Northern Ireland, though numbers of scanners vary by location. Acute hospitals with only one CT scanner are vulnerable as that scanner must be used for any emergencies. This means diagnostic appointments can be cancelled or delayed. Across the rest of the UK there is a focus on the reconfiguration and consolidation of diagnostic services into larger diagnostic centres or hubs.

Key to these pilots was the establishment of a single hub location where people could attend for a range of tests on the same day. Quick movement through the diagnostic hub is maintained by active and ongoing coordination and clinical liaison by the Clinical Nurse Specialist (CNS) and patient navigators who track and support patients throughout the process.

In Wales and Scotland, diagnostic hubs are currently focused on patients with ‘vague but worrying symptoms’.

Based on results from the ACE pilots in England, there is ongoing expansion of their diagnostic hubs to provide the same services for a wider range of patients including all those with red flag referrals. These larger diagnostic hubs will provide a single point of access to a diagnostic pathway for all people with urgent symptoms that could indicate cancer, and a personalised, accurate and rapid diagnosis of their symptoms by integrating existing diagnostic provision and utilising networked clinical expertise.

NHS England has recently accepted recommendations made by former England National Cancer Director, Sir Mike Richards, for the development of ‘community diagnostic hubs’. His recommendations included the separation of emergency and elective diagnostics to reduce patient delays, consideration of ‘alternative’ sites for diagnostic hubs (including high streets or out-of-town retail parks), increased staff in imaging and endoscopy, and purchase of additional CT scanners.

For Northern Ireland, the introduction of centralised diagnostic hubs, initially for people with vague but concerning symptoms, and then expanded to include all those with a red flag referral for cancer, has the potential to reduce the number of GP, hospital consultant and diagnostic appointments and significantly speed up diagnosis.

The development of these diagnostic hubs would mean easier and more flexible staffing and scheduling, opportunity to utilise newer techniques and technology, facilitation of clinical training and supervision and potential for improved waiting times with centralised lists and locations. Most importantly, there is the opportunity to diagnose more people early and to improve both patient experience and outcomes.

Action 15. Develop new pathways and diagnostic services to improve diagnosis.

Diagnosis of Haematological Malignancies

Malignant haematological diagnoses are based on the analysis of several different specimens (blood and bone marrow) by specialists in multiple laboratory disciplines. Together these results provide an accurate final diagnosis which informs personalised patient management.

NICE guidance NG47, updated in 2016, recommends an accredited Specialist Integrated Haematological Diagnostic Service (SIHMDS) to manage the diagnosis of all haematological malignancies. An SIHMDS for Northern Ireland would be located on a single site, have a full range of specialist diagnostic staff and be the single point of sample analysis and diagnosis for any suspected haematological malignancy. SIMHDSs exist in most other centres across the UK.

NG35[18] (developed in 2016 and updated in 2018) recommends full-body MRI scan as the first line of diagnosis for patients with suspected myeloma. Whole Body MRI (WBMRI) is not routinely offered for patients with suspected or newly diagnosed myeloma. This approach has largely been due to lack of availability of MRI scanning and reporting capacity within Trust imaging services. In the wake of the COVID-19 pandemic and the resultant impact on cancer services, it is recognised that it is no longer tenable for patients not to receive the recommended investigation of WBMRI. In the absence of additional MRI equipment and staffing, this could extend waiting times for other MRI patients and there will be additional requirements in terms of radiographer and radiologist training as well as updating of current MRI protocols.

Action 16. Develop a specialist integrated haematological diagnostics service for Northern Ireland.

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[18] Myelnoma: Diagnosis and Management, NICE Guideline NG35, 2016, https://www.nice.org.uk/guidance/ng35.

Theme 2: Diagnosing and Treating Cancer

Treating Cancer

Treatment for cancer varies by tumour type, stage of the disease, the person's general health status, age and increasingly genetic and molecular information. Patients may be offered surgery, radiotherapy, hormonal therapy, systemic anti-cancer treatment, which includes chemotherapy, immunotherapy and biologic agents. For many it will be a combination of treatments. Demographic changes in our population will result in an increased demand for high-quality, effective cancer treatments which offer the best possible outcomes.

Regardless of the treatment offered, every person should expect the highest standard of care. If the evidence base indicates that particular procedures or treatments would be optimised by centralisation on fewer sites then services will be reconfigured appropriately.

The current model of delivery for elective surgery, SACT and radiotherapy is based on a Monday to Friday model. Consideration must be given to extended provision over a seven-day model with the recognition that this will have significant implications for the workforce.

Prehabilitation

Prehabilitation enables people with cancer, prior to any type of cancer treatment, to prepare for treatment through assessment and needs-based prescribing for healthy behaviour and follow-up.

The key components are exercise, nutritional management and psychological support. Prehabilitation and rehabilitation are core elements of the pathway of care from diagnosis, and focus on enablement and empowerment. Services are led and delivered by a range of Allied Health Professionals (AHPs).[19]

Although prehabilitation guidelines, developed by the Royal College of Anaesthetists and the National Institute for Health Research Cancer and Nutrition Collaboration, in partnership with Macmillan Cancer Support,[20] were launched by the Department of Health in 2019 there is no planned, coordinated or commissioned prehabilitation service available in Northern Ireland. While some ad hoc pathways, pilot initiatives and models are developing for some tumour groups, there is minimal provision available for

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[19] Brown, H. et al. (2014) An evaluation of cancer surgery services in the UK, Health Services Management Centre, University of Birmingham, and ICF-GHK consulting.

[20] Macmillan (2019) 'Prehabilitation Guidance for People with cancer', www.macmillan.org.uk/assets/prehabilitation-guidance-for-people-with-cancer.pdf.

prehabilitation despite strong international evidence about the benefits and cost effectiveness.

Research has shown that in the absence of prehabilitation and rehabilitation programmes, functional recovery is delayed (for older patients in particular) so that six months post operatively only 50% have achieved pre-operative functional levels. Prehabilitation and rehabilitation services enable a more proactive and cost-effective care approach, with the potential to reduce the length of hospital stays, need for ICU / HDU admissions, medication and post-treatment complications, whilst enhancing recovery and quality of life overall.[21]

Action 17. Develop and implement prehabilitation and rehabilitation services on a regional basis for all those who will benefit.

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[21] NHS England NHS England (2018) 'Quick Guide: The role of allied health professionals in supporting people to live well with and beyond cancer. Transforming health, care and wellbeing with allied health professionals', London: Allied Health Professions team, https://www.england.nhs.uk/wp-content/ uploads/2018/10/quick-guide-ahp-cancer.pdf).

Surgery

Surgery is the cornerstone of treatment in the management of non-haematological cancers and for many cancers it is curative as the sole treatment. In addition, surgery may be undertaken as a preventative measure, for diagnostic purposes, reconstruction or for palliation.

Ideally surgery for cancer should be planned in advance but the reality is that many cancers still present themselves as emergencies often requiring emergency interventions. It is therefore difficult to completely separate planned and emergency cancer surgery. The nature of the most complex elective surgery means that it can never be separated entirely from unscheduled care services. For less complex surgery to be as efficient as possible, there is a strong case for attempting to insulate it from unscheduled care pressures.

The first dedicated elective care centre for Northern Ireland was recently established in South Eastern HSC Trust at Lagan Valley Hospital which has enabled the complete separation of elective and unscheduled services and has supported services to be delivered throughout the pandemic on behalf of the region. This new model continues to evolve but has already demonstrated the benefits of having dedicated elective capacity.

There is a broad consensus that surgical services should be configured to ensure that people receive the highest standard of multidisciplinary care. Evidence from elsewhere demonstrates that specialisation of services and the centralisation of complex surgery on fewer sites results in better patient outcomes for certain procedures. There is, however, a balance to be achieved through maximising resources and scarce clinical skills by specialisation and centralisation with the provision for minimally invasive and day case surgery delivered more locally.

Advances in surgical techniques and new technologies have resulted in less invasive procedures which not only reduce length of stay in hospital but also contribute to improved recovery and experience. New techniques may continue to replace the role of traditional surgical resection. This is partly due to improvements in visualisation, endoscopic and minimally invasive technology and the expanding role of robotics and nano-technology. Robotic surgery has been implemented in Northern Ireland but its use is limited currently to prostate cancer and partial nephrectomy.

Failure to introduce new surgical technologies will significantly impact on both the ability to deliver training for the next generation of surgeons and on the recruitment of new consultant surgeons. Delays in the implementation of new technology may also result in inequitable access to the best standards of care in the future.

Big data, genomics and artificial intelligence will increasingly drive developments in surgery. Increasingly, precision or personalised medicine will be based on an individual patient’s genetic, molecular and/or cellular characteristics and specific attributes of their tumour. These revolutionary changes will impact on if and when traditional surgery plays a role in treatment. While the role of surgery may diminish in the primary treatment of some cancers, greater understanding of disease biology is likely to increase the surgery in selected patients with more advanced disease.

The role of prehabilitation, with optimisation of patients prior to treatment combined with less invasive techniques, may increase the proportion of elderly or frail patients suitable for radical treatment.

Enhanced Recovery After Surgery

Enhanced Recovery After Surgery (ERAS) has been described as a paradigm shift in perioperative care, resulting in substantial improvements in both clinical outcomes and cost savings. Originally programmes were developed for colorectal surgery but have now been shown to be advantageous for almost all major surgery.

Examples of evidence-based modern care include changes from overnight fasting to carbohydrate drinks two hours before surgery, minimally invasive approaches instead of large incisions, management of fluids to seek balance rather than large volumes of intravenous fluids, avoidance of, or early removal of drains and tubes, early mobilisation, and serving of drinks and food the day of the operation. ERAS protocols have resulted in shorter length of hospital stay by 30% to 50% and similar reductions in complications, while readmissions and costs are reduced.[22]

ERAS programmes have been implemented in some areas in NI. There is a need to implement programmes regionally and at scale to ensure both enhanced patient outcomes and greater efficiencies.

Action 18. Reconfigure cancer surgical services alongside any future recommendations for the delivery of emergency and elective surgery.

Action 19. Implement Enhanced Recovery After Surgery programmes on a regional basis for all appropriate major cancer surgery.

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[22] Ljungqvist, O., Scott, M., Fearon, K.C. (2017) ‘Enhanced Recovery After Surgery: A Review’. JAMA Surg. Mar 1;152(3): 292–298. doi: 10.1001/jamasurg.2016.4952. PMID: 28097305.

Radiotherapy

Radiotherapy is a vital component of the different treatment options for cancer patients and has widespread uses in both curative treatments and for the treatment of symptoms in palliative patients. Different studies over a number of years have indicated that approximately 50% of people with cancer should receive radiotherapy as part of their primary treatment. There is also a recognised increase in the number of people who will require radiotherapy as part of a re-treatment regime. This is estimated to be approximately 25% of cancer patients, suggesting that more than 60% of people with cancer will require radiotherapy at some point during their care by 2025.[23]

Radiotherapy in Northern Ireland is delivered at two centres: the Northern Ireland Cancer Centre (NICC) at the Belfast HSC Trust and the North West Cancer Centre (NWCC) in the Western HSC Trust at Altnagelvin Hospital. The NWCC additionally provides treatments to patients from parts of the Republic of Ireland under an all-Ireland agreement. The two centres are independent with people undergoing their whole radiotherapy pathway in one or other of the centres. Transfer of patients part way through the radiotherapy pathway is not easily achieved and is subject to increased risk and would require replanning of patients with delays in restarting treatment and additional work for the receiving centre. Moving forward, both centres should work in collaboration to develop common treatment pathways and in partnership with BSO establish compatible treatment planning platforms.

Some people are currently referred for highly specialist treatments such as proton beam radiotherapy to centres in other jurisdictions. It is unlikely that the population of Northern Ireland will ever be large enough to sustain these treatments and, going forward, we will explore all-Ireland solutions for these low volume, costly treatments. Access to these treatments is often on a cost-per-case basis. This can add to delays in the patient's pathway, and adds to the administrative burden for the service.

Radiotherapy treatments are delivered over differing timeframes ranging from a single dose for palliation to several weeks as part of a fractionated treatment course.

Different cancer types, stages and sites will have different overall radiation dose and fractionation schedules associated with them. The capacity requirements on the treatment delivery units (LINACs - Linear Accelerators) will be affected by a complex relationship between the number of patients, the number of fractions and the complexity of each treatment. There is a trend towards the use of less fractions per treatment, which reduces demand on the accelerators, but there are growing numbers of more complex treatments which increase demand on the accelerators. The capacity available on the radiotherapy treatment units needs to be able to

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[23] Borras JM, Lievens Y, Barton M. et al (2016) 'How many new cancer patients in Europe will require radiotherapy by 2025? An ESTRO-HERO analysis'.

accommodate changes to this complex balance between reducing the number of fractions and increasing the complexity of the treatment.

Modern treatments can take many hours or days to plan and require highly trained staff and advanced software packages to fully exploit the potential of modern radiotherapy techniques. Each person will require some level of treatment planning. The increasing complexity of treatment impacts directly on the workload of the treatment planning staff.

Recent advances in radiotherapy have ensured more accurate delivery of treatment thus reducing long-term side effects and improving quality of life. As treatment becomes more advanced, there will be a requirement for ongoing investment. Newer treatments such as stereotactic ablative radiotherapy (SABR) are becoming more routine and their use is likely to be extended to a much wider range of tumour sites in the short to medium term. Currently there is a clear need for a rolling replacement programme for LINACs combined with investment in both software and staff training. Planning ahead for the adoption of novel technologies, such as MR simulation treatment planning in the short term and MR LINAC delivered radiotherapy in the medium term, will be essential to the delivery of world-class treatment.

Radiotherapy is a very data intensive treatment modality. This includes multiple pre-imaging data sets, both for diagnosis and treatment planning purposes, multiple treatment verification image data sets and potentially many follow-up image data sets.

To deliver a safe, quality-assured and outcome-driven radiotherapy service robust and accessible data sets are required in line with other UK countries which enable them to routinely analyse radiotherapy outcomes and to contribute to national and international audits. Commitment to a continual cycle of data review and examination is fundamental in providing learning opportunities which help to reduce cancer relapse, toxicity and improve quality of life.

Action 20. Introduce and implement new radiotherapy techniques and technology in line with national guidance including staffing and associated training.

Systemic Anti-Cancer Treatment

Systemic Anti-Cancer Treatment (SACT) is a collective term which describes all drugs used to treat cancer and includes chemotherapy, immunotherapy and targeted therapies. It can be given intravenously or orally, in hospital or in other settings. As the incidence of cancer increases and survival continues to improve, there is an associated increase in the demand for systemic anti-cancer therapy. SACT may be given on its own or in combination with other treatments and may be given with the aim of curing cancer or of prolonging life.

SACT is currently delivered in both cancer centres and in the three cancer unit hospitals, Antrim Area Hospital, Craigavon Area Hospital and the Ulster Hospital. The cancer unit service depends on visiting oncologists to provide SACT clinics as well as outpatient clinics for new and review patients. Currently, unit-based oncology consultants consist of two consultants in South Eastern HSC Trust and one consultant in the Southern HSC Trust. To prevent professional isolation and provide peer support, these posts link into audit and quality improvement, safety and educational meetings hosted through the Northern Ireland Cancer Centre (NICC). The consultants also provide clinical leadership and care for the Trust Acute Oncology Service and for patients based in the units. Looking to the future, Cancer units and the NICC should explore an expansion in further unit-based posts with associated dedicated funding.

The current service model for non-surgical oncology was established over 20 years ago. Since then there have been major developments in many areas of cancer care including imaging, pathology, genetics, surgery and treatment regimes. For many years, there have been ongoing issues with the sustainability and resilience of the service. The Oncology Services Transformation Programme (OST) reported in 2019 and was followed by the Oncology Haematology Stabilisation Plan in October 2020. OST identified a 6% projected annual growth requirement in SACT services until 2026.

Recent data has demonstrated that growth has been very significantly greater than predicted. Data from the Regional Information System for Oncology and Haematology (RISOH) demonstrates a growth of 32% in the number of oncology prescriptions between 2018/19 (when the system was brought into use) and 2021/22. Based on OST projections of 6% growth per annum, we would have expected to see a 19% increase over this period. This data demonstrates that not only is the service seeing more patients but the complexity of the patients and treatment prescribed have increased. The pressure is being felt across the entire multidisciplinary team.

While the increases have not been as dramatic within haematology, they are still well in excess of 6% per annum growth.

The project also determined that the way forward was to develop a sustainable medically-led and supported service as opposed to the current consultant-delivered model. It is essential that these plans are implemented if we are to ensure an efficient, effective and resilient service for the future. Failure to implement will mean that we do not make the most appropriate use of skills within the medical and non-medical workforces. Furthermore, the continued use of a consultant-led service will be at considerably greater cost than other models in the future.

The COVID-19 pandemic has resulted in some positive changes to the delivery of SACT services, including the delivery of certain oral SACT treatments to peoples' homes, the development of near-to-home phlebotomy services and the use of remote assessment, all of which have been well received. Learning from these developments must be used to shape services for the future. Oncology services have been maintained throughout the pandemic, but as referrals have started to recover and more people are offered SACT or radiotherapy as alternatives to surgery, the pressure is increasing on an already very fragile service.

The home delivery of oral SACT developed during the pandemic has reduced footfall in hospitals and provided convenient, safe care for patients. This could be extended to people receiving subcutaneous therapies (given by injection under the skin) who agree to and are competent to self-administer their treatment. A significant number of haematology patients are under active surveillance (watch and wait). This includes people with early stage chronic lymphocytic leukaemia and other pre-malignant conditions. Many of these people are suitable for primary care or nurse-led follow up.

Over recent years, there has been a rapid expansion in the use of oral targeted therapies and immune checkpoint inhibitors in particular. In contrast to the use of intravenous cytotoxic chemotherapy requiring specialist nursing care, many of these new treatments are either oral medications or can be administered as relatively simple intravenous infusions. The use of chemotherapy is likely to continue.

However, as a proportion of the total number of SACT delivered, its use is proportionately likely to fall over the next 10 years. This will afford the opportunity to explore the development of other models of delivery of this treatment in the future, for example delivery of treatments in health and wellbeing centres, or in non-cancer unit hospitals with day care facilities. Failure to provide SACT at home or near to home for those suitable is adding to the footfall in hospitals and is costly in both time and travel for people living with cancer.

Pharmacy

The OST programme made specific references to modernising pharmacy services. This includes the need to expand and develop the clinical and aseptic pharmacy workforce. Failure to do so may risk the sustainability of current and future services and will restrict the ability to manage both new and complex treatments and the expansion of precision medicine. There is a need to plan for a more integrated and holistic pharmacy service. This includes pharmacists undertaking clinical verification, medicines optimisation, prescribing, monitoring of patients, patient education and community liaison. Pharmacist involvement in these areas has been shown to be effective in identifying treatment and adherence issues, improving the patient experience, improving patient and carer knowledge, and making cost-effective medicines choices. The outcomes of the current review of aseptic pharmacy will be invaluable in the future development of regional pharmacy services.

Action 21. **Implement in full the recommendations of the Oncology Service Transformation Project and the Oncology Haematology stabilisation plan.**

Action 22. **Ensure timely treatment where services cannot be provided in Northern Ireland due to specialist nature of services, technology constraints or low number of patients. Continue to monitor the viability of providing these services locally including CAR-T.**

Action 23. **Develop near-to-home phlebotomy services.**

Action 24. **Review the model of delivery for Systemic Anti-Cancer Treatment services including the delivery of near/close-to-home SACT.**

Acute Oncology Services

Acute oncology services have been developed across most of the UK in response to a report in 2008 from the National Confidential Enquiry into Patient Outcome and Death (NCEPOD), which showed serious deficiencies in the care of acutely unwell cancer patients. The services exist in hospitals that have emergency departments or are specialist cancer hospitals. Their role is to address both the needs of people presenting as emergencies prior to diagnosis, as well as dealing with acute consequences of treatments provided to patients. In many cases, people are presenting with life-threatening issues such as neutropenic sepsis. Acute Oncology Services (AOS) were implemented across Northern Ireland in 2016. This represents a major step forward in the safe provision of non-surgical oncology services. To date, they have demonstrated reduced hospital stay, avoidance of admission, have expedited investigative pathways and have also shown that unnecessary investigations can be avoided. There are, however, recognised limitations to the service. Currently the service is provided across all Trusts on a five-day, 9-5 model.

Cancer registry data demonstrates that two thirds of people who would benefit are presenting outside this time frame. A National Peer Review visit in 2018 highlighted a number of serious concerns including insufficient staffing. Given the increasing incidence of cancer and number of people receiving SACT, the current AOS are not sustainable.

Cancer of Unknown Primary (CUP)

Following on from the NCEPOD Report, guidance has been developed by NICE (2010) mandating the provision of a CUP Service. Metastatic CUP is a common and well-recognised syndrome. It represents 3–5% of all malignancies and is the fourth most common cause of cancer-related death. Overall survival at 12 months is around 16%, but only 6% for those who present as an emergency. People diagnosed with CUP are known to have aggressive advanced disease, complex clinical needs, chemotherapy-resistant biology and poor clinical outcomes.

A CUP service is a dedicated specialist team aiming for improved survival-based outcomes and enhanced quality of life and patient experience. A regional CUP service for Northern Ireland should be commissioned to ensure timely diagnosis, improved survival and better outcomes for patients.

Metastatic Spinal Cord Compression (MSCC)

Metastatic spinal cord compression (MSCC) occurs when there is pathological vertebral body collapse or direct tumour growth causing compression of the spinal cord. Irreversible neurological damage ensues with resulting permanent paralysis.

The true incidence of MSCC is unknown but post-mortem evidence indicates that it is present in 5–10% of people with advanced cancer. In 2008, NICE[24] issued guidance on MSCC which recommends that patients with suspected, impending or confirmed metastatic spinal cord compression should have their care coordinated and streamlined to ensure appropriate and timely treatment, the benefits of which are earlier diagnosis and importantly improved outcomes for patients including prevention or delay in the onset of paralysis, timely rehabilitation and significantly reduced length of stay in hospital.

Without access to a regional MSCC coordination service, the pathway for these people is fragmented resulting in potentially delayed diagnosis, poorer survival outcomes and sub-optimal quality of care for those with limited life expectancy.

Action 25. Develop a 24/7 metastatic spinal cord compression service with rapid access to imaging and treatment.

Action 26. Extend the acute oncology service across all Trusts to seven-day working.

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[24] NICE (2008) 'Diagnosis and management of adults at risk of and with metastatic spinal cord compression' http://www.nice.org.uk/CG75.

Precision Medicine

In the last decade, molecular pathology and diagnostics has successfully been implemented in health services, resulting in a dramatic change in the access to new targeted drugs for people with cancer. The expansion from the current molecular pathology structure to a more holistic genomic medicine approach is inevitable in the next few years, and it is supported UK-wide through several white papers and more recently through the transformational activities of the 100,000 genomes project led by NHS England. Northern Ireland is a part of this project via recognition as a Genomic Medicine Centre.

Precision medicine will become increasingly important in determining the most appropriate management plan for people with cancer. Improvements in technology mean that molecular profiling will become available at a relatively low cost and information will be available within clinically-relevant timeframes. The long-term vision for Precision Cancer Medicine in Northern Ireland is for all cancer patients to have access to high- quality, comprehensive and timely molecular characterisation of their tumour to inform therapeutic and clinical management. However, Northern Ireland lags behind other regions of the UK in developing this service.

The systematic application of genomic technologies has the potential to transform lives by:

- Enabling a quicker diagnosis for patients with a rare disease
- Matching people to the most effective medications and interventions, reducing the likelihood of an adverse drug reaction
- Increasing the number of people surviving cancer each year because of more accurate and early diagnosis and more effective use of therapies

Going forward, Molecular Tumour Boards will be established to provide advice to multidisciplinary teams (MDTs) in determining appropriate management options and prognosis. These services should be fully incorporated into all aspects of cancer pathways including diagnosis and screening services, therapeutic decisions, monitoring of response, relapse or recurrence. Embedding genomic testing in routine patient management, including generic consent, would generate an efficient pathway for the implementation of precision cancer medicine.

It is important to ensure that people and their families are well informed of the benefits and consequences of genomic testing, particularly in regard to the risks of pertinent findings (i.e. genetics variants linked to cancer predisposition such as BRCA1/2, MHL1).

Action 27. Deliver genetic and genomic testing in cancer pathways in line with NICE recommendations.

Haematological Cancers

Haematological cancer, otherwise known as blood cancer, is a broad term which refers to cancer which primarily affects the blood or blood-producing organs. These cancers range in complexity and prognosis with some being low-grade chronic conditions to aggressive life-threatening conditions. Treatment also varies significantly from surveillance, outpatient chemotherapy and immunotherapy, to intensive and complex including stem cell transplantation.

Haematology services are provided within all Trusts. Specialist level 3 care is provided at Belfast City Hospital (BCH). Data demonstrates an increase in new referrals to haematology services in Northern Ireland of 42% between 2013 and 2018. The associated day-patient activity has increased by 22.9% over the same time period and inpatient activity has increased by 32%. This regional specialist unit generally runs at 120–130% capacity with outlying patients in the Northern Ireland Cancer Centre.

Currently, the BCH site provides autologous haematopoietic stem cell transplantation (auto-HSCT) and sibling allogeneic transplantation (allo-HSCT). Patients undergoing Matched Unrelated Donor (MUD) transplant receive pre-transplant work-up and post- transplant follow-up in BCH but they must travel to another centre such as St James's Hospital in Dublin or a London-based transplant unit to undergo the procedure. The number of people undergoing auto-HSCT is rising year on year. In 2019, the transplant service was unable to meet the demands and as a result, patients were transferred to King's College Hospital, London for transplantation. In order to meet the ever-increasing demand for haematopoietic stem cell transplantation and avoid travel outside of Northern Ireland, expansion of transplant capabilities at BCH is required.

NICE guidance (NG-47) clearly defines the facilities required to provide level 3 care including single occupancy rooms with individual bathrooms and clean air systems. NG47 also stipulates the need for onsite contiguous access to critical care along with respiratory and cardiology specialities to safely care for patients receiving higher intensity SACT and transplant.

Chimeric Antigen Receptor T cell Therapy (CAR-T) has emerged as a promising new treatment for some blood cancers in both children and adults. Approval in the UK has been given for the treatment of follicular and mantle cell lymphoma with other approvals expected in the short term. The clinical indications for this intervention continue to expand and it is likely that it will rival and possibly replace autologous HSCT in some instances.

Some 30% of patients undergoing CAR-T require ICU admission during their inpatient stay. A multiprofessional approach is required for the safe management of these patients including timely input from critical care, renal, neurology, cardiology and allied healthcare professionals.

At present this treatment is only available at a small number of highly specialised centres in other jurisdictions. Relatively small numbers of adult patients are referred annually for CAR-T but numbers are expected to rise significantly in the coming years. CAR-T is also licensed for use in the treatment of children and young people.

Travel for people can be challenging given their underlying diagnosis and usually involves at least two to three visits to a GB site before CAR-T takes place. Following the procedure, people spend three to four weeks in hospital before returning home.

New models of care for haematology need to be developed including ambulatory and Out of Hours (OOH) facilities. This would enable a reduction in the numbers of people being delayed from hospital at discharge, the timely management of neutropenic sepsis and other life-threatening complications and people being inappropriately admitted to hospital.

Electronic prescribing of SACT for haematology patients was highlighted as a major concern during the SACT peer review 2019. This limits data collation and comparison of patient outcomes. Standardised electronic prescribing systems have been shown to reduce the risks of SACT-related incidents. An electronic prescribing system must be fully implemented for all haematology patients.

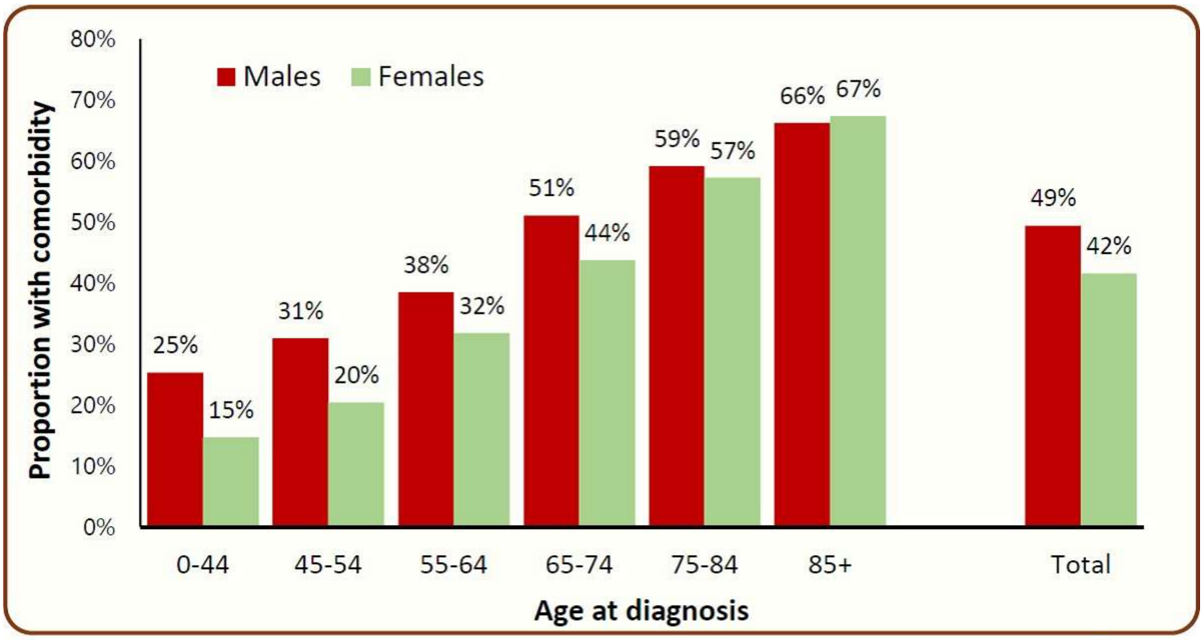
Action 28. Develop ambulatory care haematology units in each of the Trusts and establish near-to-home treatment services for suitable patients.

Action 29. Implement a safe and robust electronic prescribing system for all Systemic Anti-Cancer Treatment regimes.

Older People with Cancer

Cancer is a disease related to ageing and increases in incidence in older adults. 2015 figures for the UK show that 36% of people diagnosed with cancer were over 75 years of age. It is estimated that by 2035, this proportion will rise to 45% and will account for 65% of cancer deaths.[25] The Cancer Research UK report ‘Advancing Care, Advancing Years: Improving Cancer Treatment and Care for an Ageing Population’ notes that age is a proxy measure for complexity as increasing age is associated with increased comorbidities, cognitive issues and complex social care needs. This is illustrated using data from the Northern Ireland Cancer Registry. These issues will require significant consideration in the development of cancer treatment and care plans. Like all other age groups, the needs of people vary. Many older people are active and in good health while others are frail with multiple other long-term conditions.

Figure 6: Age and Co-morbidity. Northern Ireland Cancer Registry



Note: Includes cancers (ex. NMSC) diagnosed in 2016, with comorbidities up to one year before diagnosis.

Source: Northern Ireland Cancer Registry

Research by the National Cancer Intelligence Network in England (2015)[26] has highlighted the fact that older people are more likely to have their cancer diagnosed late and to present as an emergency.

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[25] Smittenaar CR, et al. (2016) Cancer Incidence and Mortality Projections in the UK Until 2035. Brit J Cancer 115, 1147-1155

[26] National Cancer Intelligence Network (2015) ‘NCIN, Older People and Cancer (version 3)’.

There is evidence of age-related inequality in cancer outcomes with reduced cancer-specific survival in older patients and also evidence of discrepancy between outcomes in older people in the UK compared to the best performing nations.[27] [28] [29] There is no reason to believe the position in Northern Ireland differs from that in any other UK nation.

There is evidence that older people are less likely to receive different types of treatment which may be a result of individual choice, because they are too unwell for active treatment or because they choose quality over quantity of life. It may be due, at least in part, to them not being offered treatments due to assumptions made about fitness for treatment based on age. The assessment and care of older people with cancer are complex and have given rise to the specialty of geriatric oncology supported by its own international association, the International Society of Geriatric Oncology (SIOG).

Methods currently used routinely to assess fitness for treatment are, arguably, not fit for purpose and lead to poor assessment of the needs of older people with cancer. There is also a lack of evidence about the benefit of certain cancer treatments in the elderly who are not adequately represented in clinical trials.

Care of the Elderly Services should be better integrated with oncology and haematology. The identification of frailty is largely based on assessment of performance status, is a visual assessment and does not usually rely on more accurate validated frailty screening tools.

In addition to the risk of under-treatment in older people, there is a risk of overtreatment without the use of appropriate geriatric assessment screening tools to identify those older people in need of a more thorough assessment of frailty. Getting the balance right to ensure appropriate treatment, either curative or with palliative intent, is difficult but nonetheless vital.

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27 Coleman, M.P. et al. (2011) 'ICBP Module 1 Working Group, Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995–2007 (the International Cancer Benchmarking Partnership): An analysis of population-based cancer registry data', The Lancet, vol. 377: 127–38.
28 Berrino, F. et al (2007) 'Survival for eight major cancers and all cancers combined for European adults diagnosed 1995–99: results of the Eurocare-4 study'. The Lancet Oncology, 8, 773–83.
29 Woods LM, et al.(2009). 'Large differences in patterns of breast cancer survival between Australia and England: a comparative study using cancer registry data'. International Journal of Cancer, 124, 2391–9.

Adults with Learning Disabilities, Communication Needs and Chronic Mental Health Problems

Outcomes for people with cancer who suffer chronic mental ill health are poorly understood. There is data to suggest that they are more likely to present with advanced stage cancer and, stage for stage, have worse cancer-specific outcomes than the general population.[30] Similar evidence exists for people with learning difficulties.[31] Furthermore, people with mental ill health problems have higher rates of health behaviours linked with cancer mortality including cigarette smoking and excess alcohol use and may experience bias in the consideration of symptoms they complain of.

For those with learning difficulties and other communication issues including dementia, it most often falls to carers, family or other healthcare professionals to notice changes that require investigation. In order to enable early diagnosis, it is important to make these carers and others aware of the signs and symptoms of cancer.

The delivery of cancer treatment for people with learning difficulty or mental ill health is potentially complicated with issues around their capacity to understand and consent to treatment. This may require formal assessment of capacity and careful decision making with the person, supported by their family. There must be better collaborative working between cancer services, learning disability and mental health services to improve outcomes for these groups of people.

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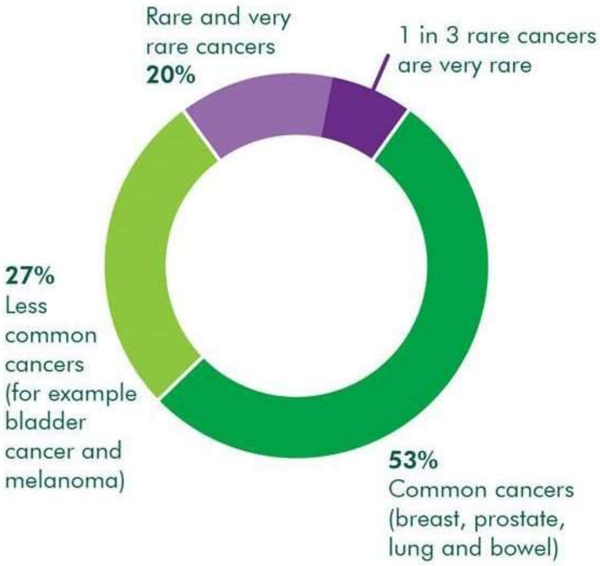
30 Cunningham, R. et al. (2015), ‘Cancer survival in the context of mental illness: A national cohort study’. General Hospital Psychiatry 37 (2015) 501–506.
31 Hafeez, S. Singhera, M. and Huddart, R. (2015) Exploration Of The Treatment Challenges In Men With Intellectual Difficulties And Testicular Cancer As Seen In Down Syndrome: Single Centre Experience’, BMC Medicine 13:152

Rare Cancers

Four main cancers: breast, bowel, lung and prostate make up 53% of all cancers. Less common cancers such as melanoma and bladder account for 27% with the remaining 20% accounted for by rare and very rare cancers. A cancer may be rare because of where it is, if it affects a child, teenager or young adult or it may be a subtype of a more common cancer.

Figure 7: Rare cancers – proportions of common, less common, rare and very rare cancers. Macmillan Cancer Support



By their nature, rare cancers can be harder to diagnose. Treatment tends to be complex and services are usually centralised in highly specialised centres. People may have surgery, SACT or radiotherapy provided in specialist centres outside of Northern Ireland. There is a need for comprehensive patient pathways for diagnosis, treatment and follow-up care with a particular emphasis on good multidisciplinary team working.

Metastatic Cancer

Cancer which spreads to another part of the body from its initial site is called metastatic cancer. Treatments are available to either slow the progression of the disease or to improve quality of life by treating the symptoms. The treatment offered will depend on many factors including previous treatment, general health status and personal choice. In common with other stages, treatment offered may include hormonal therapy, chemotherapy, immunotherapy, radiotherapy and surgery. Unfortunately for many, metastatic cancer will ultimately be terminal but a growing number of people, with the appropriate treatment and care, are living for many years.

Currently data is not collected for people with metastatic disease in a systematic way for all cancer types. This must be included as an integral part of the development of mandated data sets for cancer. Accurate data will support the development of evidence-based services for the future.

There is a need to develop regional MDTs for people with metastatic disease to ensure evidence-based optimal treatment and care and to enable access to clinical trials.

Action 30. Develop appropriate pathways and accessible services for older people with cancer, adults with learning disabilities, communication needs and chronic mental health problems, rarer cancers and metastatic cancer.

Children and Young People

Childhood is a time of very rapid development and change. What happens in childhood has a life-long impact and affects life chances and outcomes.

Spending long periods in hospital or at home feeling ill can seriously affect a child or adolescent's development and outcomes. Special care and resources are needed to support ongoing development and education during this time. The social and emotional needs of children, adolescents and their families must be taken account of and supported during cancer treatment.

The guideline for children's cancer services NICE CSG 7: Improving Cancer Services for Children and Young People with Cancer was published in 2005 and reviewed in 2015. This guideline recommends that care across the UK should be coordinated from designated centres.[32] Under the auspices of the Children's Cancer and Leukaemia Group (CCLG) care is delivered through 19 Principle Treatment Centres (PTCs) led by professional experts in childhood cancer shaping a future where all children survive and live happy, healthy and independent lives.

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[32] 'National Institute for Health and Clinical Excellence, 2005, Improving Outcomes in Children and Young People with Cancer -The Manual' pdf. https://www.nice.org.uk/guidance/csg7.

Children diagnosed with cancer up to the age of 16 will have their care coordinated by the PTC at the Royal Belfast Hospital for Sick Children (RBHSC).

A diagnosis after the age of 16 will mean care is provided by the regional Cancer centre in BHSCT and/ or one of the regional adult cancer units depending on the diagnosis and treatment.

> *“High levels of expertise, but facilities really letting the services down.”*

Built as an eight-bedded unit, capacity in RBHSC was increased to 10 beds in 2018. A separate day-care unit was designated in 2013 to meet the increased demand, and in 2020, this facility was further developed.

Based on current bed occupancy and predicted need, the new children’s hospital, expected to open in 2027, will have 13 inpatient beds for haematology and oncology and an eight-bedded unit.

> *“I don’t think we have coped. I think we have survived by taking it one day at a time.”*
>
> - *parent*

The PTC offers a range of Systemic Anti-Cancer Therapies (SACT) including chemotherapy, radiotherapy, immunotherapy, and Autologous Haemopoietic Stem Cell Transplant.

The centre also offers a portfolio of clinical trials for a range of haematological and oncological conditions. A nurse-led telephone triage trial service is key to this acute service, with SACT-trained nurses assessing the need for telephone advice or direct access to the centre for those requiring face-to-face assessment or admission.

However, it does mean that families from outside Belfast must travel to RBHSC for all treatment and care – possibly passing other hospitals with children’s wards and services on the way. There is a need to explore options for the development of shared-care services for procedures such as blood tests and oral chemotherapy outside of Belfast.

"Belfast seems far away at 2am, when your child's temperature is rising and you have to travel."

"The fact that it was a drive down the road to Dublin as opposed to an air ambulance to Bristol or across the water was a big benefit to us."

The provision of highly specialist treatments such as allogenic haemopoietic stem cell transplant, proton beam therapy, specialist surgery or early-phase clinical trials is provided in specialist centres outside of Northern Ireland.

Children will follow an initial treatment plan in Belfast and on return will have step-down care and any further treatment. It is essential that appropriate support is provided for both children and parents when receiving care outside of Northern Ireland. Many parents have highlighted the challenges of being away from home with a seriously ill child for months at a time, in particular the separation from their other children and wider family support. In addition, many families struggle financially as one parent often has to leave work to care for the ill child or young person.

There is a desire to explore the possibility of developing an all-island service for paediatric oncology to improve outcomes for children, young people and their families.

The treatment and care provided by the health and social care team in RBHSC is supplemented by services provided by a range of charities. These include the funding of core specialist posts and the provision of many therapeutic services for both children, young people and their families.

Play specialists organise a wide range of activities but many of the activities are primarily aimed at pre-school-aged children who tend to be the biggest group of children on the ward at any one time. It can be very isolating for older children and young people when they are in hospital for long periods.

Many former patients and parents highlighted a lack of age-appropriate activities and environment for older children on the ward.

Action 31. **Every child, young person and adult diagnosed with cancer, and their carers, will have access to staff with the specialist knowledge and skills to provide developmentally appropriate, person-centred care.**

Action 32. **Increase collaboration between Northern Ireland, Great Britain and the Republic of Ireland in the provision of children's oncology services.**

Teenagers and Young Adults (TYA)

The most common cancers in this age group are leukaemia, lymphoma, thyroid cancers, brain and spinal cord tumours, testicular and ovarian cancers and sarcoma. Treatment is currently delivered in all Trusts with specialist and complex services provided in the Northern Ireland Cancer Centre, Belfast Trust.

Due to the specific age-appropriate needs of teenagers and young adults, TYA cancer care is a distinct speciality. Cancer is a rare disease in this age group and therefore the young people become a rarity amongst their peers. Their specific needs are both psychosocial and physical. TYA with cancer interact with many services including haematology, oncology, medical and surgical specialities, psychology, psychiatry, palliative care, social work, youth work and education. Their care also transcends professional, organisational and geographical boundaries.

It is acknowledged that, in some parts of the UK and Ireland, age criteria may vary and there may be some flexibility in age boundaries of services to ensure that individual patients can access the optimum disease and age-appropriate services.

TYA cancer patients fall within both paediatric and adult cancer services. Evidence indicates the care needs of this group of people as being separate from children and adults, requiring a multidisciplinary approach incorporating both disease- specific and age-specific expertise.

Charitable funding has enabled the provision of TYA Clinical Nurse Specialists (CNS) in each Trust, who, as part of the multidisciplinary team, ensure young people are supported throughout the treatment pathway. This includes coordinating investigations, fertility preservation prior to treatment and referral on to other services. Funding for other key posts and services is provided by a range of cancer charities. There is no regional TYA MDT in Northern Ireland, and very few named clinicians with responsibility for TYA.

The European Society for Medical Oncology have highlighted a range of issues for TYA patients including the lack of equitable access to specialised, age-appropriate centres with age-appropriate multidisciplinary care and the lack of available clinical trials with novel treatments. It states that survival gains have improved only modestly compared with older adults and children with cancer. Other findings from ESMO highlight deficiencies in access to both specialist facilities and to support from a wide range of healthcare professionals including specialist nurses, AHPs, social workers and psychologists. They go on to advocate a strengthened multidisciplinary approach with greater involvement of both paediatric and adult oncologists and haematologists with expertise in treating adolescents and young adults.

The ESMO working group who have developed this paper specify minimum essential criteria for adolescent and young adult cancer services, which, in addition to effective multidisciplinary team working and access to clinical trials, include fertility preservation, age-appropriate psychosocial support, age-specific environments, access to siblings and peers, age-specific palliative care, late-effects services, provision of social activities and education.

Services in Northern Ireland fall short of these recommendations.

> *"Being treated in an adult environment because I was 16, I was neither child nor adult"*

> *"We never got support. It was all given to our son. We didn't know about how to budget, how to access services for our other kids. They and we were struggling too."*

> *"Hospital felt like another world, one that we had not yet learnt the language of."*

Transition

Cancer services for teenagers and young people are becoming much more aware of the importance of patient choice while they navigate multifaceted care and treatment pathways.

Transition can be a stressful and anxious time for young people and their parents or carers. They may be unsure about what to expect, proposed treatment plans and what help may be available to them in order to plan for their future.

The arrangements for the transition of TYA vary given the complexity of this age group. Transition may be from the Royal Belfast Hospital for Sick Children (RBHSC) paediatric services to adult services, from a regional hospital to the Northern Ireland Cancer Centre (NICC), from NICC back to a regional hospital. For significant numbers, it also involves moving to hospitals outside of Northern Ireland for specialist treatment and then back again.[33]

In addition to the multiple transitions through health and social care, consideration should also be given to the 'normal' transitions of childhood and adolescence such as education, further education and employment. Cognitive impairment due to treatment may be a significant factor for some children and young people with brain tumours. In order for all children and young people living with cancer to realise their potential, better integration between services is required.

Well-established transition models, which are largely nurse-led exist elsewhere in the UK and Ireland and learning from these will be beneficial in developing an appropriate service in Northern Ireland.

Action 33. Review the provision of services for teenage and young adults in Northern Ireland including transition arrangements, age-appropriate environments, psychological support and long-term follow up.

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33 (GOSH 2011). The Adolescents and Young Adults with Cancer.

Multi-disciplinary Teams (MDTs)

Multi-disciplinary Teams (MDTs) working through Multi-disciplinary Meetings (MDM) bring continuity of care and reduce variation in access to treatment – and ultimately improve outcomes for patients. They have been in place in Northern Ireland for the last 20 years. The membership of MDTs is in keeping with NICE Improving Outcomes guidance. Cancer MDTs have been subject to an ongoing process of MDT Peer Review since 2013 which has been funded by Macmillan Cancer Support.

Teams, which include medical specialities, nursing and AHPs, are under increasing pressure due to the growing number of cancer diagnoses, the increased number of treatment options and greater need for a co-ordinated approach to cancer management between specialties. Reform of the current MDT system is required to ensure they remain effective and efficient and that adequate time is available for the discussion of complex cases. Time for MDT meetings requires adequate recognition in the job plans of all MDT members and, where required, preparation time for these meetings.

There has been work to develop referral proforma for MDMs and management protocols; however, these have not been universally adopted. All discussions at MDMs are captured on the Cancer Patient Pathway System (CaPPS) and outcomes are generally communicated to GPs within 24 hours of the MDT occurring, although this is not always the case.

Whilst it is expected that all people newly diagnosed with cancer will be discussed at an MDT meeting, there is no formal requirement to discuss people with relapsed or progressing cancer. This could lead to variations in access to treatment and a lack of consideration of all treatment options available. A programme of audit of management decisions for MDTs should be introduced and consideration should be given to the introduction of MDT morbidity and mortality meetings which have been established in England.

Action 34. An effective Multi-disciplinary Team meeting will be held for all people diagnosed with cancer including cancer of unknown primary and metastatic disease.

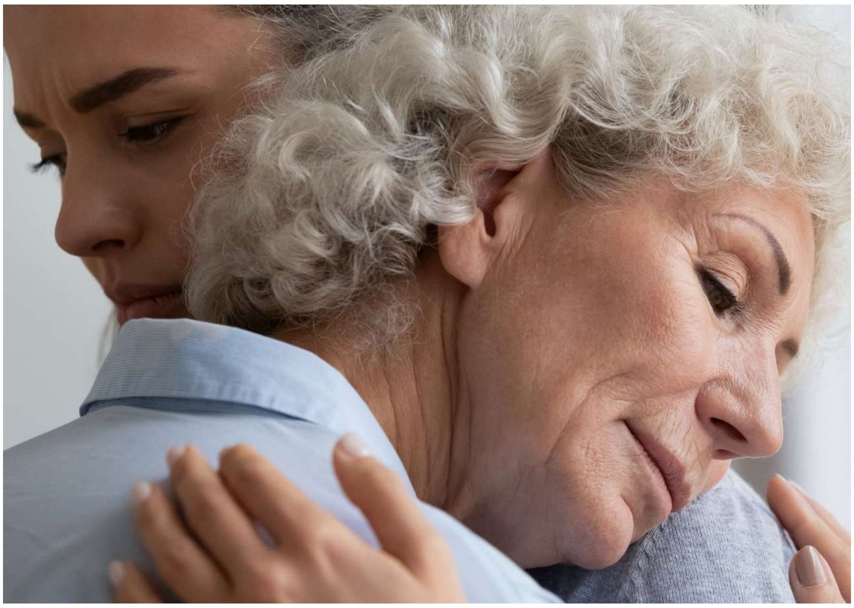
Theme 3: Supporting People to Live Well and Die Well

Supporting People

People affected by cancer include patients, family members, carers and staff, all of whom will require support at different times, in differing formats and at varying levels. People diagnosed with cancer will require care and support at all stages of their cancer journey from diagnosis, through treatment, living with and beyond cancer and, for some, into palliative and end-of-life care.

The HSC is committed to a person-centred approach which aims to put the public, patients, their carers and staff at the heart of cancer services and empower managers and healthcare professionals to commission, plan, monitor and deliver effective and efficient services of the highest quality. No two people are the same, either in their cancer or their health and care needs. When care is truly person-centred, people are treated as individuals, with compassion, dignity and respect. The impact of cancer extends beyond the physical effects of the disease to include psychological, social, economic and spiritual consequences for people living with cancer and their carers.

There needs to be a sustained focus on enabling, supporting and empowering people to make informed decisions about their treatment and care and supporting them to self-manage in the longer term.



‘Person centeredness is an approach to practice through the formation and fostering of healthful relationships between all care providers, service users and others significant to them intheir lives. It is underpinned by values of respect for persons (personhood), individual right to self-determination, mutual respect and understanding.[34]

The approach of focusing on integrated personalised care for people with cancer across health settings has been adopted by Macmillan through the Recovery Package. People with cancer, and particularly those who are also managing other long-term conditions, will interact with other services. Research has shown that one of the strongest predictors of good patient experience is overall coordination of care. In the most recent Northern Ireland Cancer Patient Experience Survey (2018), only 72% of participants felt that all those involved in their care worked well together to deliver their care.[35]

“I would have ‘loved’ if someone sat down with him and said this is the ‘rough plan’ and what will possibly happen.

“The professionals worked well with the individual patient, but ‘fell down’ in terms of communicating with each other about the patient.”

The Recovery Package is a series of key interventions which, when delivered together, greatly improves outcomes for people living with and beyond cancer. The components of the Recovery Package are outlined in the table below and contain: Holistic Needs Assessment (HNA) and Care Planning, Treatment Summary Records (TSR), Cancer Care Review (CCR), Health & Wellbeing interventions and Risk Stratification. This has been implemented at varying levels across the four nations of the UK and continues to evolve as more data is generated. Implementation of the Recovery Package is a core part of both the English Cancer Strategy (2015) and Long-Term Plan (2019). The subsequent Comprehensive Model and

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[34] McCormack, B. and McCance, T. (2017) Person-Centred Practice in Nursing and Health Care: Theory and Practice. Oxford: Wiley Blackwell.

[35] Public Health Board HSCNI (2019)‘Northern Ireland Cancer Patient Experience Survey 2018 All Trusts Report - Draft v0.3’ https://www.publichealth.hscni.net/sites/default/files/2019-01/Northern%20Ireland%20Cancer%20Patient%20Experience%20Survey%202018%20All%20Trusts%20Report.pdf.

Personalised Care (2019) looks at how person-centred care can be integrated and delivered across four domains: acute, primary, community and digital.

An Integrated Assessment Map (IAM Portal [36]) developed by Teenage Cancer Trust is an age-specific, multi-domain framework which provides a structure to support professionals, teenagers and young adults in holistically assessing needs for information and support at any point in their cancer journey. It is designed to look at the impact of and adjustment to their cancer and its treatment within a bio-psycho-social-educational-vocational framework – i.e. what does having this cancer and its treatment mean for this young person and their support network at this point in time. Teenage Cancer Trust is implementing the IAM Portal across the UK and this should be implemented in Northern Ireland.

> *"I love the idea of an electronic treatment summary record. At the minute I'm the one who seems to need to be in control."*

Macmillan Recovery Package	
Holistic Needs Assessment (eHNA) and CarePlanning	A supported conversation using a structured electronic questionnaire to identify needs, facilitate discussion and agree the best way to meet them from the person's perspective. It ensures that physical, practical, emotional,spiritual and social needs are identified in a timely and appropriate way, and that resources are targeted at those who need them most.
Treatment Summary Records (TSR)	A pro forma document which records clear information about a person's treatment, any immediate to longer-term consequences of treatment that they need to be aware of, on-going clinical management, any actions they need to take and who to contact with any questions or concerns. It is completed after a significant phase of a person's cancer treatment. A copy is provided to the person living with cancer and their GP.
Cancer Care Review (CCR)	CCRs involve a person with cancer having a holistic conversation with a primary care healthcare professional

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[36] Teenage Cancer Trust (2022) https://www.iamportal.co.uk.

	in order to discuss issues relating to their cancer or treatment.
Health & Wellbeing interventions(H&WB)	The aims of Health and Wellbeing (H&WB) interventions are to educate people with cancer on how to live well, inform people with cancer about where they can access the support they need, help people with cancer to cope with difficulties (e.g. stress/anxiety, diet, consequences of treatment/late effects), provide targeted information to people with cancer, and provide opportunities for people with cancer and their carers to access peer support.
Risk Stratification	An approach to profiling people following treatment for cancer that is based on their clinical and individual needs. Itis appropriate for all people whether they have been treated with curative or palliative intent.

Ultimately, the Recovery Package seeks to provide the support that people living with cancer need to lead their best possible lives. Full implementation of the Recovery Package can ensure that, from diagnosis or soon after, people's needs are identified and addressed.

Data from electronic Holistic Needs Assessment (eHNA) will be a key resource in the development and improvement of cancer services for the future and will enable benchmarking between services, across cancer types, Trusts and the four nations of the UK. There are benefits to eHNA being embedded in the ongoing development of Encompass.

With increasing numbers of people surviving their cancer diagnosis, cancer follow-up in primary care is likely to resemble that of other chronic diseases. Healthcare professionals must be encouraged to provide a TSR and CCR to everyone who has been diagnosed with cancer.

Health and wellbeing events should continue to provide a forum by which attendees can receive information on how to self-manage their condition. These events must be offered for all cancer types.

Risk-stratified Follow Up

The traditional model of oncology follow-up clinics is being challenged like never before. Demand for outpatient appointments is increasing as more people are living with a cancer diagnosis; however, many follow-up appointments would appear to offer little value to the patient. This is due, in part, to traditional oncology follow-up clinics having focused mainly on detection of cancer recurrence and less so on the comprehensive range of health-related quality-of-life (QOL) issues.[37] Many cancer survivors attending these clinics report ongoing, unidentified and unmet needs.

In addition, recent studies have highlighted a feeling of abandonment from patients during the transition period from cancer patient to survivor.[38] Needs inevitably change as people move along the pathway demanding a more tailored approach to care. Self- management is in place for many breast cancer patients and this should be extended to other cancers where clinically appropriate. This would reduce the need for hospital appointments and would enable resources to be redistributed to diagnosing more new patients and supporting those with metastatic and complex disease.

Appropriate follow up is essential to ensure monitoring of a person's clinical condition and timely investigation of possible disease relapse or progression. A stratification of risk allows the clinical team, and the person living with and beyond cancer, to make a decision about the best form of aftercare. This is based on knowledge of the disease (the type of cancer and what is likely to happen next), the treatment (what the effects or consequences may be both in the short and long term) and personal clinical circumstances (whether they have pre-existing illnesses or conditions, and how much support they feel they need).

Models of aftercare include:

- Supported self-management – Individuals are given information about:
    - Self-management support programmes or other types of available support
    - Clinical signs and symptoms to look out for
    - Who to contact if they notice anything of concern
    - Scheduled tests they may need (such as annual mammograms)
    - How to contact relevant professionals if they have any concerns
- Shared care – people continue to have face-to-face, phone or

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[37] Jefford, M., Rowland, J., Grunfeld, E. et al. (2013) 'Implementing improved post- treatment care for cancer survivors in England, with reflections from Australia, Canada and the USA', British Journal of Cancer, 108, 1: 14–20.

[38] Davies, N., Batehup, L. (2011) 'Towards a personalized approach to aftercare: A review of follow-up in the UK', Journal of Cancer Survivorship, 5, 2: 142–151.

email contact with professionals as part of continuing follow up. Nurse-led follow up is a shared care approach recognising the extended role of the nurse. A systematic review[39] concluded that nurse-led care can be more beneficial than doctor-led care in terms of physical outcomes, psychosocial aspects of care and patient satisfaction, whilst not impairing the long-term survival of patients with cancer. Local evaluations have demonstrated effective nurse-led follow-up.[40]

> ***"There are some fabulous things [learnt from the pandemic]. I am having my check-ups via Zoom, being sent for scans at the local hospital, so didn't have to go to Belfast. There are things that are really working well."***

- Hospital-based care – people with more complex conditions and needs who remain under the care of the consultant.

- Emerging models which involve new joint multi-professional clinics, such as post radiotherapy for people recovering from head and neck cancer led by a Clinical Site Specialist Radiographer and CNSs. There is potential to further develop these models to include the management of late effects and consequences of treatment.

Prior to the COVID-19 pandemic, some follow-up monitoring was being undertaken by CNSs via telephone. As a direct consequence of the pandemic, the use of technology in follow-up care has increased significantly. Further work needs to be carried out to establish which modality is best, for which patients and to understand which member of the team is best suited to carry out the review. Training for staff, the development of protocols and agreement on the appropriate technology will be required to develop this further to ensure the optimum experience for both people living with cancer and staff.

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[39] Caird, J., Rees, R., Kavanagh, J. et al. (2010) The Socioeconomic Value of Nursing and Midwifery: A Rapid Systematic Review of Reviews, EPPI Centre, Social Science Research Unit, Institute of Education, University of London.

[40] Semple, C.J. & Lynas, C. (2018) 'Development, integration and evaluation of nurse- led follow-up across five tumour sites at a cancer unit in Northern Ireland', Cancer Nursing Practice, doi: 10.7748/cnp.2018.e1460.

Action 35. **Develop a person-centred model of care that builds on learning from COVID-19 with increasing use of telehealth and technology.**

Action 36. **Offer all people a holistic needs assessment, an appropriate care plan and provide signposts to relevant sources of help and support.**

Action 37. **Develop a comprehensive treatment summary record for all people diagnosed with cancer.**

Action 38. **All people who have completed cancer treatment will be assessed and risk stratified to appropriate follow-up pathways.**

Support from Clinical Nurse Specialists

Cancer Clinical Nurse Specialists (CNSs) play an important role in the management of individual patients as their key worker.[41] They are a core member of the multidisciplinary team (MDT), and as such, each MDT is required to have a Clinical Nurse Specialist in order to meet accepted MDT peer review standards. Data from the Northern Ireland Cancer Patient Experience Study (2018) clearly demonstrates that the support of a CNS is the single most important factor in a patient's experience of care. However, not all patients have access to a CNS and for many, the support is limited to the diagnostic and surgical part of the service.

CNSs should be available across the cancer pathway, through diagnosis, treatment for primary and metastatic disease and throughout follow up. This applies to all children diagnosed with cancer and their parents and includes a dedicated TYA CNS service to support teenagers and young adults throughout their care. CNSs have a key role in: ensuring that all people with cancer have their holistic needs assessed, the development of personalised care plans and facilitating self-management and appropriate longer-term follow up.

Action 39. All patients, including children and young people, diagnosed with cancer will have access to a Clinical Nurse Specialist throughout the entire care pathway.

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[41] NHS (2011) 'Quality in Nursing Excellence in Cancer Care: The Contribution of the Clinical Nurse Specialist', https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/Clinical-Nurse-Specialists-in-Cancer-Care_Census-of-the-Nurse-Workforce_Eng-2011.pdf

Mental Health and Wellbeing Support

Stress and distress are a common response to a diagnosis of cancer, not only for the patient, but also for the families.

Research carried out by Macmillan indicates that 21% of people living with cancer experience problems with poor mental health and that 73% of people living with cancer report some type of emotional concern, most commonly worry, fear and anxiety, sadness, depression or loss of confidence. Data shows that circa 70% of people diagnosed with cancer have other long-term conditions to manage alongside their cancer.[42]

Mental ill health cross cuts the entire cancer pathway. Some services are offered by the voluntary sector but outside of this provision, formalised pathways do not exist for cancer patients. A mental health Strategy has been developed to address existing inequalities; however, we know that services in each of the Trusts are overwhelmed, no clear pathways from cancer services exist and this has a significant impact on primary care workload. Promoting good mental health and preventing mental ill health from developing amongst those living with cancer, as well as ensuring adequate management of conditions should they occur are important in the provision of holistic cancer care. The number of people needing help with their mental health is likely to grow as more people are living longer following a cancer diagnosis. There are significant gains to be realised both in patient quality of life and savings in health -care costs.

A cancer diagnosis often brings a significant change to family dynamics and research shows that family members can often display higher levels of anxiety and depression than patients themselves.[43]

Referrals to psycho-oncology services have risen sharply in recent years with disparity in provision between Trusts and long waiting lists in several areas. In addition to an increase in referral rates, there may be need to prioritise certain groups of people diagnosed with cancer, due to an increase in risk factors:

- Teenage and Young Adults (TYAs)
- Pregnant women and new mothers
- People awaiting assessment in advance of prophylactic breast surgery in line with NICE guidelines (CG164). People awaiting risk-reducing surgery must be seen within a reasonable timeframe to avoid delays in completing surgery and possiblecancer diagnosis in the interim period.

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[42] Macmillan Cancer Support (2020) ‘Prevalence - People living with cancer ’. https://www.macmillan.org.uk/_images/cancer-statistics-factsheet_tcm9-260514.pdf.

[43] Mullen, L. & Hanan, T. (2019) National Cancer Survivorship Needs Assessment: Living with and beyond cancer in Ireland, Dublin: National Cancer Control Programme, https://www.hse.ie/eng/services/list/5/cancer/profinfo/ survivorship-programme/living%20with%20and%20 beyond%20cancer%20in%20 ireland.pdf.

- People receiving palliative care and those at end of life (NICE 2004; 2008). It is essential that people who are receiving palliative care are seen before they become too fatigued or unwell,to be able to engage in psychological assessment or therapy.

Pathways will be developed for the screening, assessment and management of mental ill health.

Services to support mental health and wellbeing will typically receive patient referrals following diagnosis on completion of treatment, at diagnosis of cancer recurrence/relapse and for people receiving palliative and end of life care. NICE (2004) also describes the need for care and support of the diagnosed patient's family and carers, and this is especially true in the case of children and young adults diagnosed with cancer (NICE, 2005).

Counselling supports people dealing with the emotional impacts of cancer. A range of cancer charities across Northern Ireland provide counselling, both in hospitals and in the community, specifically to people with cancer and their families.

Alternative therapies can also provide help and support. For example, creative arts therapies comprise music therapists, art therapists and drama therapists who are skilled clinical healthcare professionals. They can help reduce anxiety, pain, tiredness and increase wellbeing and often provide the opportunity for people and their families to express feelings and emotions which are often impossible to express verbally. Such therapies may therefore provide support to promote good mental health and may provide alternatives to traditional services.

Whilst there is an array of services available across health and social care and in the community, awareness and access to services remain a challenge for many. Services provided by the voluntary sector are largely self-funded through fundraising activities. In addition, the reduction in counselling provision during the COVID-19 pandemic has negatively impacted on the waiting times for clients and has further added to their emotional distress.

It is essential that all people affected by cancer are able to access different types of support, provided by the appropriate person, dependent on their level of need in a timely manner.

Action 40. In alignment with the mental health strategy develop a model to promote good mental health and wellbeing for people affected by cancer and develop pathways to ensure that all people with cancer have access to mental health support in line with their needs.

Information and Therapeutic Support

Staff from all sectors who interact with people and their families play a key role in the provision of information and support. All Trusts have designated specialist services which lead on the provision of high-quality information and support. In addition, both local and national cancer charities have a focus on the provision of information and support services, many providing information via helplines, online fora and via social media channels which HSC is not resourced to do. Collaborative working to maximise resources is essential to ensure all those who need information get it when and where required.

> ***"I found the period of greatest anxiety to be between receiving the diagnosis and getting into hospital. There was a 'period of waiting between, with millions of questions' i.e. Who do I go to? What's going to happen? What is the process?"***

An independent evaluation of Trust Information and Support Services was undertaken in 2019 and the report makes a series of recommendations to ensure that all people are routinely referred to information and support services.[44] These include the increased use of digital applications, integration of social prescribing, improved provision for carers and enhanced partnership working with the community and voluntary sector.

> ***"You still have to pay the bills and support the family. It is hard to juggle commitments with work. There are so many emotions and a lot of pressure."***

Many people will seek information from pre-diagnosis particularly when they are referred by their GP for further investigations. Specific information resources must be developed and provided to all

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[44] Macmillan Cancer Support (2020) Evaluation of Macmillan Information and Support Services in Northern Ireland, Rocket Science.

patients at this early stage, specifically for those people who are referred via the ‘red flag’ route.

Information for people living with cancer goes far beyond the physical implications of cancer. Provision must be holistic in nature and encompass financial and benefits advice, employment issues and support for carers.

It is imperative that there is equitable provision of information and support for all sections of society including those who do not have English as their first language, people with a learning or sensory disability and age appropriate information for children, teenagers and young adults. We must also ensure that all people diagnosed and treated in the independent sector have access to the full range of information and support services.

Currently over a third of those living with cancer in Northern Ireland are of working age. Cancer can have a major impact on a person’s ability to work and while most wish to stay in or return to work, many do not receive the information, advice or rehabilitation support they need to help them do so. This results in people falling out of work, having a major impact on individuals, families and employers. Significantly, there is strong evidence to suggest that remaining or returning to work can promote recovery and lead to better clinical and psychosocial outcomes.[45]

Spending long periods in hospital or at home can seriously impact on children and young people’s developmental and educational outcomes. Special care and resources are needed to support ongoing development and education during this time. Currently, support for education is variable and there are particular challenges for young people aged 16–18.

The social and emotional needs of children and their families must be taken account of and supported during cancer treatment. The need to invest in and strengthen social and emotional support for children, young people and their families was one of the strongest messages coming from our engagement with people with lived experience.

Benefits advice services, hardship grants to patients and financial guidance are a vital means of supporting people facing the financial hardships caused by cancer. Services are currently available in all Trusts but are provided and predominantly funded on an annual basis by voluntary sector organisations with no agreed recurrent funding streams.

Therapeutic services is an umbrella term which represents a wide range of support services. This includes complementary therapies, self-management programmes and support groups, practical support, creative therapies, pain and symptom control, lifestyle change supports, chaplaincy services and helplines. Specific services for children and young people include short breaks, peer mentoring and educational events. The vast majority of these

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[45] Waddell, G., Burton, A.K. (2006) Is work good for your health and well-being? London: The Stationery Office

services are provided in the community by the voluntary sector. Post pandemic, many of these services are at risk due to the impact on fundraising for almost all charitable organisations. Better integration and collaboration will be essential to ensure the sustainability of many therapeutic services for the future.

Action 41. All people with a cancer diagnosis will be referred to a Cancer Information and Support Service at diagnosis.

Action 42. Timely and appropriate access to therapeutic and practical support services for people affected by cancer targeting emotional, physical, spiritual and social needs will be provided.

Carers

Support and care provided by families and informal carers is vital to the wellbeing of patients given their assistance in managing medications, treatment regimes, symptom management, personal care, social and psychological support. Providing informal care is challenging for many and can have a negative impact on both physical and mental health. Evidence has shown that there is a need to deliver improved services for informal carers of patients with cancer in Northern Ireland.[46] [47] [48] [49] Healthcare professionals have a responsibility to ensure that carers' needs are assessed and that they can obtain information easily across the illness trajectory with adequate signposting to additional support. Cancer Caring Coping[50] is a co-designed, one-stop, online, multi-medium resource (www.cancercaringcoping.com) tailored to support carers of adults in Northern Ireland from diagnosis to possible bereavement. This resource should be made available to all carers. In addition to support from social work teams, a wide range of support is provided by cancer charities for parents and carers of children and young people.

In addition, people providing unpaid care for loved ones with non-curative cancer and at end of life should have access to support services to meet their own health and wellbeing needs. This includes regular breaks from caring and reliable respite care.[54]

Whilst carers in all situations face challenges, there is a particular need to ensure appropriate support for parents of children and young people with cancer. Services and facilities including overnight accommodation are predominantly funded and provided by charities. There is a clear need for much better partnership working and integration with statutory services to ensure that all families get the support they need across the entire pathway

Support for staff working in cancer services must also be considered. Research has shown that good staff experience contributes to better patient care. Emphasis should be placed on readily accessible up-to-date information, support and advice.[51]

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46 Santin, O., Murray, L., Prue, G., Gavin, A., Gormley, G., Donnelly, M. (2015) 'Self- reported psychosocial needs and health-related quality of life of colorectal cancer survivors', European Journal of Oncology Nursing, 24: 121–129.

47 Santin, O., Mills, M., Treanor, C., Donnelly, M. (2012) 'A comparative analysis of the health and wellbeing of cancer survivors to the general population', Journal of Supportive Cancer Care, 20,10: 2545–2552.

48 Treanor, C., Santin, O., Mills, M., Donnelly, M. (2012) 'Cancer survivors with self-reported late effects: Their health status, care needs and service utilisation', Psycho-oncology, 22: 2428–35.

49 Santin, O., Treanor, C., Mills, M., Donnelly, M. (2014) 'The health status and health service needs of primary caregivers of cancer survivors: A mixed methods approach', European Journal Cancer, Volume 23, Issue 3: 333–339.

50 Santin, O., McShane, T., Hudson, P., Prue, G. (2018) 'Using a six-step co-design model to develop and test a peer-led web-based resource (PLWR) to support informal carers of cancer patients', Psycho-oncology https://doi. org/10.1002/pon.4969

51 Marie Curie (2018) 'Lost retirement: The impact on older people of caring for someone with a terminal illness' https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-

Supporting People to Live Well

Whilst more people than ever are surviving after a cancer diagnosis, not everyone who has survived is living well. Over half of those diagnosed with cancer today will live for at least 10 years and for some types of cancer, the figure is much higher. Contributions from people living with cancer to the development of this Strategy have consistently demonstrated that surviving is very different from living well. Research carried out by Macmillan in 2013 found that at least one in four people living with cancer faces poor health or disability following treatment for cancer. Many people will make a good recovery following treatment but a significant proportion will continue to live with a wide range of problems. People who have had curative treatment can be left with disabling, chronic long-term conditions as a result. As there are no agreed pathways in place, their treatment and care are often poorly managed, disjointed and uncoordinated.

A significant proportion also live with the increased risk of developing cardiac, bone and bowel problems as a direct consequence of their treatment, some of which will not become apparent until many years later. Up to 75% of children and young people who have been treated for cancer will have long-term consequences of cancer including a greatly increased risk of developing a second cancer. Survivors of childhood cancer are three times more likely to die 35 years after diagnosis than peers without a cancer diagnosis.[52]

> ***"I feel that at the end of treatment we were just left."***

> ***"I feel I am managing well, but the management of my health has been all consuming and has taken over my life due to the severe impact of surgeries and treatments. I had to take early retirement."***

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publications/lost-retirement-the-impact-on-older-people-of-caring-for-someone-with-a-terminal-illness.pdf.

[52] Ruelen, R.C., Winter, D.L., Frobisher C. et al. (2010) 'British Childhood Cancer Survivor Study Steering Group. Long-term cause-specific mortality among survivors of childhood cancer', JAMA, 304(2): 172–9.

There are many treatments used to manage a diagnosis of cancer including surgery, radiotherapy, chemotherapy, immunotherapy and hormonal therapy. These can be used alone or in combination, often over a prolonged period of time. Side effects are part of any treatment regime but for the purposes of this section, the focus is on the longer-term, chronic effects of treatment.

> ***"I want to live life, I want to have fun. Still have the craic. This is my view and it has been for the last while."***

There is a gap in the knowledge and understanding of late effects and consequences of treatment, particularly in light of an ageing population. Many people live with their problems, often struggling to get the right treatment and support, and many are unaware that help is available, assuming that the symptoms are the cost of a cure. As more people survive cancer, the problems associated with late effects, consequences of treatment and long-term follow up will grow. This comes at a high cost to both the individual and to health and social care. Not only is this an issue for the quality of life of those affected, it is also a major challenge for the timely provision of long-term, tailored care and support. Currently services either do not exist or are not resourced to meet the growing demand. This is compounded by a lack of available data to quantify the numbers of people affected.

Cardiovascular

The European Society of Medical Oncology (ESMO) consensus paper of 2020[53] states 'with increasing numbers of cancer survivors living longer, oncologists and other health care providers are faced with challenges in managing long-term and late toxicities of therapy, recognizing that cardiovascular issues are significant causes of morbidity and mortality in this population.'

There is robust, compelling international evidence about the growing impact of cancer treatments on cardiovascular health. Next to cancer recurrence, progression and second malignancies, the leading cause of death in cancer survivors is cardiovascular diseases (CVDs) due to the intense oncological treatment which many people receive. A significant number of anti-cancer therapies are associated with some level of cardiovascular toxicity, ranging

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[53] ESMO (2020) 'ESMO Consensus Guidelines 2020 Management of cardiac disease in cancer patients throughout oncological treatment: ESMO consensus recommendations – ScienceDirect' https://www.annalsofoncology.org/article/S0923-7534(19)36080-6/fulltext.

from asymptomatic and transient to long-term permanent life-threatening problems.

In a recent report, the American Society of Cardiology[54] states that ‘the management of cancer can no longer be limited solely to the active treatment of malignancy, we must invest in additional research and foster multidisciplinary collaboration to tackle gaps in our knowledge and ultimately improve both cancer and cardiovascular-related health outcomes in this growing population.’

Children and young people, in particular, are at serious risk of premature death in later life from cardiovascular and respiratory failure as a consequence of treatment[55] Some pathways are currently in place for this group of patients but this is not a commissioned service. Cardiovascular oncology is an emerging specialism with dedicated services developing in other parts of the UK.

In Northern Ireland, increasing numbers of people living with cancer who are at risk of developing cardiovascular disease due to treatment are being referred to cardiology services, which is having a major impact on waiting lists and access to services such as echocardiograms. It is estimated that circa 3000 echocardiograms are done for oncology patients per annum.

Bone Health

Hormonal therapy is a main stay of treatment for both breast and prostate cancers, often resulting in inevitable osteoporosis. This is also the case for people who have prolonged treatment with steroids. Pathways are in place for monitoring bone density for people living with breast cancer but there are no existing pathways for men living with prostate cancer or others at high risk.

Significant numbers of people develop metastatic bone disease which, for many, can be managed over a period of years. Over successive years, there has been a steady increase in referrals to orthopaedic services combined with a significant workload managing long bone fractures and spinal cord compression. Access to appropriate palliative care can be an issue for people with long bone fractures who are initially managed in acute orthopaedic wards. There is no commissioned service in place for the management of metastatic spinal cord compression.

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54 Tan, C MD & Denlinger C. MD (2018) American College of Cardiology Cardiovascular Toxicity in Cancer Survivors: Current Guidelines and Future Directions https://www.acc.org/latest-in-cardiology/articles/2018/06/29/12/57/cv-toxicity-in-cancer-survivors.

55 Mulrooney, D.A. et al. (2009) ‘Cardiac Outcomes in a cohort of adult survivors of childhood and adolescent cancer: Retrospective analysis of the Childhood Cancer Survivor Study cohort’, BMJ 339: b4606.

GI Consequences of Pelvic Radiotherapy

Although more people are surviving cancer, problems associated with pelvic radiotherapy are presenting many years (up to 5-10 years) post treatment which has obvious consequences for individuals who have had treatment and for service provision. Many people report severe and distressing symptoms such as faecal incontinence, urgency, bleeding, flatulence and pain. Given the time from initial treatment, often neither the person nor primary care teams are aware that this is a likely late effect of radiotherapy treatment.

A regional task and finish group was established to develop guidelines and pathways for the management of the consequences of pelvic radiotherapy. The NICaN GI Consequences of Pelvic Radiotherapy Task and Finish Group Report was published in 2017 but, to date, has not been implemented in all Trust areas.

Elsewhere in the UK, Centres of Excellence for the management of pelvic radiation disease are being established to manage the most complex cases. In addition to the establishment of Trust pathways, consideration should be given to the development of a regional service for those with complex problems.

Sexual Health and Fertility

Cancer treatment can have devastating physical and psychological consequences on sexuality and fertility for many people. There may be a wide range of issues including erectile dysfunction, early menopause, body image issues due to disfiguring surgery, loss of libido, reduced fertility and, for some, infertility.[56]

No formal, coordinated services or pathways exist and undoubtedly the impact of cancer treatment on sexual health is unreported.

> ***"'Did you want to have any more children?' That was the only communication I had regarding fertility."***

There are particular issues for children and young people diagnosed with cancer. Established pathways to the regional facility centre are in place which are very responsive when time is of the essence to start cancer treatment. For pre-pubescent children, research-based interventions are becoming available in Oxford and Edinburgh. Consideration should be given as to how

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[56] Belfast Health and Social Care Trust (2017) 'Has Cancer affected your sexuality, sex life and relationships', Belfast: Belfast Health and Social Care Trust; Katz, A. (2005) 'The Sounds of Salience: Sexuality Information for Cancer Patients', Journal of Clinical Oncology, 23(1): 238-241.

children in Northern Ireland can avail of these in a timely manner. Every young person commencing treatment should be offered the opportunity to talk about their fertility options and how their prognosis may or may not affect that.

At present, as for all cases, people who are infertile because of their cancer are entitled to one cycle of IVF. The recent commitment within New Decade, New Approach to fund three cycles of IVF treatment will have a positive impact in this area.

Diabetes

The relationship between diabetes and cancer is complex. Observational studies suggest that cancer outcomes are poorer in patients with diabetes. It is suggested that improving glycaemic control may improve cancer treatment outcomes.[57]

Approximately 22% of patients undergoing cancer treatment have a pre-existing diagnosis of diabetes.[58] Approximately 10% of patients not known to have diabetes will develop it during their cancer treatment.[59] [60] This may be as a direct effect of the cancer or as a consequence of the treatment (such as after surgical resection of the pancreas or as side effects of the SACT regimen). Glucocorticoid medications (steroids) are a significant contributor to hyperglycaemia in SACT.

Recently guidance specific to patients with cancer has been published jointly by the UK Chemotherapy Board and the Joint British Diabetes Societies for Inpatient Care.[61] This document recommends three steps to manage patients undergoing SACT:

- Screening to identify patients at high risk of developing complications
- Providing a glucometer and educating high-risk patients in its use
- Management of hyperglycaemia

At present, there is no resource within cancer services to provide this care. It is currently done as an emergency referral to diabetes services. As screening is not taking place routinely, we suspect that there are large numbers of

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[57] Jacob, P., Chowdhury, T.A. (2015) 'Management of Diabetes in Patients with Cancer', Q J Med. 108: 443–448.

[58] Habib, S.L., Roina, M. (2013) 'Diabetes and risk of cancer', ISRN Oncology 583786

[59] Pilkey, J., Streeter, L., Beel, A., Hiebert, T., Li, X. (2012) 'Corticosteroid-induced diabetes palliative care', J Palliat Med. 15(6): 681–9.

[60] Gannon, C., Dando, N. (2010) 'Dose-sensitive steroid-induced hyperglycaemia', Palliat Med., 24(7): 737–9.

[61] Joint British Diabetes Societies for Inpatient Care Guidelines Group and UK Chemotherapy Board (2021) The management of glycaemic control in patients with cancer, London: Joint British Diabetes Societies for Inpatient Care.

patients who progress through their oncology treatment with hyperglycaemia without being identified. A pilot scheme is in place at the Northern Ireland Cancer Centre and clinics are having a significant positive impact on patient care but are currently unfunded. In addition, all Trusts are reporting significant increases in referrals to community Diabetic Specialist Nurse Services. Funding will be required to implement these services in both secondary and primary care province-wide.

Lymphoedema

Lymphoedema can develop when lymph nodes or lymph vessels are removed or damaged. It is a permanent, often disabling condition and cannot be cured. With appropriate support, many people are able to manage their condition with a regimen of meticulous skin care, exercise and wearing compression garments. It is commonly associated with breast, head and neck, and gynaecological cancers. There has been a commissioned lymphoedema service in place since 2008 with services provided in all Trusts for both malignant and benign conditions. Referral numbers have increased year on year resulting in long waiting lists and funding has not kept pace with the growing demand. Evidence from the National Cancer Action Team in England shows that investment in lymphoedema services is extremely cost effective and significantly reduces the number of hospital admissions.[62]

Neuropathy

Surgery and radiotherapy for cancer can damage nerve tissue in the targeted treatment areas, and chemotherapy may affect systems throughout the whole body. Nerve damage may be central – with brain effects of loss of cognition and memory, reduced hearing, vision, taste and smell; and/or autonomic – with changes in heart and blood pressure regulation, poor gut function: and/or peripheral – with reduction of normal sensation and motor function of the limbs, increased abnormal sensation and pain, and increased fatigue from loss of function or difficulties in coping with the burden of altered sensation. Some will reverse or decrease over time but many are permanent, causing significant disability. Nerve damage from cancer treatment is enhanced by pre-existing nerve dysfunction due to stroke, injury, diabetes and other conditions.

Studies show that following chemotherapy, 60% of people experience peripheral neuropathic pain three months after treatment, and that it

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[62] National Cancer Action Team (2013) 'Cancer Rehabilitation, Making Excellent Cancer Care Possible'.

persists for 30% at six months. Overall, between 33% and 40% of cancer survivors suffer from chronic pain.[63] [64]

Specialist palliative care clinicians and AHPs have an invaluable role to play in the management of cancer pain, not limited to end-of-life care. There is a need for better integration and collaboration between palliative care, oncology, haematology and pain management teams.

The Faculty of Pain Medicine of the Royal College of Anaesthetists published ‘A Framework for Provision of Pain Services for Adults Across the UK with Cancer or Life- limiting Disease’ in 2019. This presents a framework and operational guidance for improving pain services for adults across the UK with cancer or life-limiting disease and should be used to develop services across Northern Ireland.[65]

Respiratory

Breathlessness can have many causes including damage to the lung by cancer treatments (radiation pneumonitis, chemotherapy fibrosis and surgical scarring), loss of physical fitness/de-conditioning, disease progression, end-of-life symptoms and other co-morbidities. There are no formal pathways for treating breathlessness as a consequence of cancer treatment or disease progression. Traditionally, referrals are made later in the patient journey when patients are short of breath at rest. Earlier referrals would improve quality of life and maintain independence for many.

Chronic Fatigue

Cancer-related fatigue (CRF) is the most commonly reported symptom affecting quality of life and ability to function. Fatigue affects large numbers of people after cancer treatment but for some it persists as a chronic long-term condition. Due to difficulties with identification, problems can often go unreported and as a result, unaddressed.

No formal commissioned services exist; where support exists it is often an add-on to other services, tumour-dependent or provided by charities. Simple interventions such as physical activity have been shown to significantly reduce levels of fatigue.

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[63] Paice, J.A. (2011) ‘Chronic treatment-related pain in cancer survivors’, Pain, 152(Supplement): S84–S89.

[64] Seretny, M., Currie, G.L., Sena, E.S., Ramnarine, S., Grant, R., MacLeod, M.R., Colvin, L., Fallon, M. (2014) ‘Incidence, prevalence, and predictors of chemotherapy-induced peripheral neuropathy: A systematic review and meta-analysis’, Pain, 155(12): 2461–2470.

[65] Faculty of pain medicine of the Royal College of Anaesthetists (2019) ‘Framework for pain services cancer and life limiting disease 2019.pdf’, https://fpm.ac.uk/sites/fpm/files/documents/2019-07/Framework%20for%20pain%20services%20cancer%20and%20life%20limiting%20disease%202019.pdf

Continence

Surgery, radiotherapy or disease progression can result in bladder and bowel incontinence, affecting both males and females, and can be seriously life changing. Conservative services (e.g. lifestyle advice, pads etc.) are available but do not actively treat the condition. BHSCT successfully piloted the physiotherapy management of continence due to prostate cancer, and is now an award-winning service. Similar charity-sponsored pilots are ongoing for the therapeutic management of incontinence related to colorectal and gynaecological causes; these are not yet commissioned.

Action 43. **All people starting cancer treatment will have their health status assessed and recorded and a plan developed to mitigate potential late effects and consequences of their treatment.**

Action 44. **Develop a regional, multidisciplinary approach to the identification and management of all people at risk of late effects and consequences of their cancer treatment.**

Action 45. **Identify people deemed to be at highest risk for late cardiovascular effects and enrol them in a follow-up programme.**

Action 46. **Screen children to detect early, subtle cardiac abnormalities that might be treated, or may be reversible. In addition, where children are treated with anthracyclines or cardiac radiation they will have lifelong screening.**

Caring When Cancer Can’t be Cured

Cancer is the largest cause of death in Northern Ireland. The most up-to-date figures are circa 4,500 deaths per year with slightly more men than women dying from cancer.

Findings from the Northern Ireland Health Inequalities report for the period 2017–2019 show that among people aged under 75, the death rate from cancer in the most deprived areas was greater than the least deprived areas by a factor of 1.7.

Numbers of children and young people are small, with on average nine children and seven young adults dying annually.

Average Number of Cancer Deaths in Children & Young Adults Recorded in Northern Ireland by Age Band for the Period: 2014–2018			
	Age Band		
	0-15	16-24	Total
Average number of cases per year	9	7	16
Total	43	33	76

The Department’s vision for palliative care is that any person with an advanced non-curative condition lives well and dies well irrespective of their condition or care setting.

> ***“Everyone has a right to palliative care and a dignified passing, both for them and their families.”***

This requires a philosophy of palliative and end-of-life care that is person- centred and which takes a holistic approach to planning, co-ordinating and delivering high-quality reliable care, enabling people to retain control, dignity and, crucially, choice in how and where their care is delivered to the end of their life.

It means being sensitive to the personal beliefs, cultures and practices of individuals and their families and carers and recognising the contribution good palliative and end-of-life care can make to the quality of their lives.

Additionally, it means that where the person’s preference is to receive care, and where possible to die at home, the infrastructure and opportunities are in place to make such a choice real and viable. Palliative care is defined as: ‘the active, holistic care of patients with advanced progressive illness’. Management of pain and other symptoms and the provision of psychological, social and spiritual support is paramount. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments. More recently the importance of ‘early identification and impeccable assessment’ has been added to this definition as it is thought that problems at the end of life can have their origins at an earlier time in the progression of the illness and should therefore be recognised and dealt with sooner.

Palliative care can, in some cases, mean a shift from a curative focus towards an approach which seeks to alleviate and prevent the escalation of symptoms. The transition between curative and palliative care is often blurred, which emphasises the importance of communication between the individual and the healthcare professional with regard to the intention of treatment. Identifying this transition informs thoughtful decision-making about the appropriateness of proposed treatment options and explores the provision of further social and spiritual support to address emotional, psychological and practical needs, invaluable to the individual, their family and carers in managing the condition.

End of life is described as the period of time during which an individual’s condition deteriorates to the point where death is either probable or would not be an unexpected event within the ensuing 12 months; however, a specific timescale cannot always be applied. This point will be different for each individual and will often depend on an assessment of an individual’s condition by health and social care professionals, carers and/or the patient themselves. Identifying the point at which illness becomes advanced or reaches the end-of-life phase allows health and social care providers to plan best care with people in order to meet their needs and those of their families and carers throughout the last phase of life and the experience of bereavement. As with palliative care, end-of-life care also includes physical care, management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

Palliative and end-of-life care is provided in many settings: at home, in hospitals, in care homes and hospices. Whilst much of the formalised care is provided by multidisciplinary teams of health and social care professionals, families, carers and volunteers continue to be the crucial cornerstone of this care. The majority of children and young people die either at home or in hospital.

Number of Cancer Deaths in Children & Young Adults Recorded in Northern Ireland by Place of Death for the Period: 2014–2018

	Age Band		
	0-15	16-24	Total
Home	19	12	31
Hospital	19	15	34
Hospice	5	6	11
Total	43	33	76

Within this Strategy, we refer to people with ‘non-curative cancer’. By this we do not mean every patient whose cancer cannot be fully treated, but those with a non- curative diagnosis who have been identified as potentially benefiting from a palliative care approach. Increasingly people are living with non-curative cancer for prolonged periods of time. This has been termed ‘treatable but not curable cancer’ and includes many blood cancers, metastatic cancers including breast, bowel and prostate cancer. Growing numbers of people will receive life-prolonging treatment over many years and may require palliative care input on an episodic basis over a more prolonged period of time. Support from many professionals, including a wide range of AHPs, is critical in the management of symptoms and maintenance of a good quality of life. It is essential that referrals are made in a timely manner to ensure that appropriate support and care are provided.

Existing pathways and criteria are not always flexible enough to ensure people can access palliative care services when and where they need them. If alternative services were available this could avoid unnecessary attendance at hospital and admission for some people.

COVID-19 has significantly disrupted key cancer services which is resulting in more people presenting with advanced disease. This raises challenges for the provision of palliative care service delivery in the short to medium term.

Identification of Palliative Care Needs

There are a number of benefits from the early introduction of palliative care for people living with cancer, including integration alongside active treatment. Timely access to palliative cancer care can result in better quality of life, lower rates of depression, longer survival and higher satisfaction with care among patients. Access to palliative care is, however, dependent on both clinicians and patients and carers recognising and accepting that they could benefit from this approach. It also requires close, integrated working between key HSC disciplines, for example oncology and palliative medicine.

In practice, it would appear that both cultural and structural barriers are stopping this from happening for some patients, namely:

- The emphasis of many clinicians may be on treatment or survivorship, with a reluctance to refer to palliative care or acknowledge the severity of a patient's prognosis, as this would represent 'giving up'. This may foster an attitude where palliative services are only considered once all active treatment options have been exhausted. Misconceptions about palliative care also exist among patients and their loved ones.
- Late identification of palliative care needs often means those people, who are still deemed as curative, no matter how small the likelihood, may miss out on receiving palliative care and support services. As a result, some people and those important to them are often shocked by rapid deteriorations and feel unprepared for the end of life.
- Late identification also decreases opportunities for advance care planning and steps to facilitate the person's preferred place of care, as well as leading to complex grief in those left behind.

Recent retrospective audits (2019, pre-COVID-19) of people presenting to emergency departments have found 20–30% of people being admitted to hospital following an attendance at ED have unidentified or unmet palliative care needs. Of those admitted, on average, 40% had advanced cancer.

Action 47. Deliver integrated, coordinated and personalised palliative and end-of-life care to people with non-curative cancer when and where they need it.

Access to Palliative Care Key Workers

People are likely to receive care and support from a range of professionals including district nurses, GPs, AHPs, social care workers, their community pharmacy and specialist palliative care professionals. Care may also be provided by a range of organisations including hospices and charities. Patients and families report that it is often confusing having so many different people involved and that communication between services can be fragmented. Living Matters Dying Matters recommended that palliative care patients should be allocated a key worker to co-ordinate care, support and information. To date this has not been implemented uniformly across all Trusts and for all patients.

Action 48. All people with non-curative cancer will have access to a palliative care key worker.

Access to Generalist and Specialist Palliative Care Services

Statistics for 2019 show that 47% of all deaths in Northern Ireland occur in hospitals, 19% in care homes and 34% in all other places. The‘all other places’ for 2019 isn’t broken down in the official statistics but we know from previous analysis that around 3% of those deaths will have been in hospice and circa 27% in the person’s own home.

Socioeconomic factors may have a particular impact on the end-of-life experience of people in their own homes. Marie Curie’s research has shown that people with terminal conditions – including cancer – may be more likely to live in fuel poverty and suffer the damaging consequences of living in cold housing.[66] Elsewhere, wider UK studies have found that people in the most deprived areas are more likely to die in hospital than those in the least deprived.[67] [68]

> ***“This is my dying wish – that I get to have my final days and hours spent in comfort in my own home with my loved ones.”***

The delivery of high-quality palliative and end-of-life care requires multidisciplinary input. Specialist palliative care professionals will play an important role, but much of the care that people will receive, including at the end of life, will also be provided by wider ‘generalists’ – including GPs, district nurses, AHPs and social care workers.

Specialist Palliative Care AHP teams have a significant role in supporting people with complex palliative care needs to remain in their preferred place of care by offering palliative rehabilitation, symptom management and education for the patient, carers and health and social care professionals. Not all Trusts have community specialist AHP teams with referrals being made to generalist teams.

The need for education and training for staff, from basic understanding of what palliative care is and when it is appropriate, identifying need, advance care planning, local referral processes and integration with oncology services through to care in the last days of life and bereavement is vital if care and co-ordination are to be improved.

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[66] Marie Curie (2020) ‘The vicious cycle of fuel poverty and terminal illness’. pdf https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2020/fuel-poverty-and-terminal-illness.pdf

[67] National End of Life Care Intelligence Network (2012) ‘Deprivation and death: Variation in place and cause of death’. https://www.scie-socialcareonline.org.uk/deprivation-and-death-variation-in-place-and-cause-of-death/r/a11G00000017z9GIAQ

[68] Macfarlane, M. and Carduff, E. (2018) ‘Does place of death vary by deprivation for patients known to specialist palliative care services?’ BMJ Support Palliat Care, 8 (4).

Out-of-hours (OOH) advice and support from specialist palliative care professionals and a palliative care pharmacy is not routinely available to all health and social care teams in all locations across Northern Ireland. Where advice is available, this is usually done on an ad hoc, historical or good will basis. Specialist palliative care provision is currently only available on a Monday–Friday 9–5pm basis with no formalised out-of-hours provision.

In addition, there are challenges in ensuring equitable access for all sections of the population, particularly seldom-heard and underrepresented sectors, e.g. LGBTQ+ people, those from ethnically diverse backgrounds, people with cognitive impairment such as those with dementia, those experiencing homelessness, people in long-term institutional care including prison care, the ageing and frail population, and those living in rural and remote areas.

Action 49. Extend palliative and end-of-life support and continuity of care to seven-day working for all people with non-curative cancer.

Advance Care Planning (ACP)

In Northern Ireland, there remains a significant taboo around discussing death and dying. This inevitably can result in conversations about palliative care being put off until the advanced stages of a person’s condition, because of the association with the end-of-life stage. This can foster an attitude where palliative services are only considered once all active treatment options have been exhausted.

Advance Care Planning is an umbrella term covering personal, legal, clinical and financial planning. It enables a person to think about what is important to them and plan for their future. It is a voluntary process and helps a person to make known what their wishes, feelings, beliefs and values are, and to make choices that reflect these. A person’s Advance Care Planning conversations, any recommendations and/or decisions will be used in the future should a person become unable to make the relevant decisions for themselves. Advance Care Planning is important for every adult at any stage of life and ideally should happen before any crisis, such as the diagnosis of a serious illness. It plays an important role in ensuring that a person is given the opportunity to be involved in shared decision making and to state preferences and wishes which can be recorded and communicated to these involved in their care. People with communication difficulties may need additional support to make informed decisions or communicate their wishes.

The Department of Health Advance Care Planning policy provides a framework for Advance Care Planning for adults (aged 18 years and over), focusing on the health and social care aspects. The policy aims to support a person to have greater choice and control over decisions, including plans for their future care and treatment. Provisions for children and young people with palliative needs are outlined in the Department of Health’s strategy: Providing High Quality Palliative Care for Our Children.

Education and training should equip health and social care staff to have regular, meaningful, timely, realistic and practical conversations with people about their diagnosis, prognosis, treatment options and planning for the future. It is particularly important that communication with patients and loved ones is carried out in a sensitive and compassionate manner.

Action 50. Increase awareness and uptake of advance care planning for all people with non-curative cancer.

Pre-bereavement and Bereavement Support

Most bereavement services in Northern Ireland are provided by the community and voluntary sector. Capacity is an issue, with long waiting lists in many areas. Capacity issues are also preventing Trust social work teams from offering greater levels of bereavement support, including follow-up services with carers and loved ones. Patients and their loved ones may have access to chaplaincy support in the hospital setting, but these services will normally cease after discharge, so continuity of care does not continue into the community. Day-to-day support is likely to have been provided via the services delivered to their loved one but these are withdrawn after death. The loss of this support network can compound feelings of loneliness and isolation among recently bereaved carers.

Access to pre-bereavement and bereavement support is crucial to meet the holistic needs of carers and loved ones. It is vital that we adopt a wider approach and ensure that those important to the person living with cancer, including children, are not forgotten. This type of early intervention and support can be helpful in preventing mental health issues connected to early/traumatic loss and complex grief reactions.

Action 51. All people living with non-curative cancer, and those important to them will have access to the bereavement, psychosocial and counselling support appropriate to their needs and preferences before and after death.

The actions outlined for palliative and end-of-life care align closely with the regional priorities of the Palliative Care in Partnership (PCiP) programme and many are already included in the regional palliative care work plan. The PCiP programme is well established and would be well placed to oversee the implementation and delivery of these actions. The recently re-established bereavement group will be taking forward the development of bereavement services for Northern Ireland and our expectation is that this will include services for cancer.

Theme 4: Implementing the Strategy

Workforce and Training

Cancer services are struggling to deliver in a timely manner, with escalating waiting lists in many areas including diagnostics and surgery. The immense pressures the HSC, including all those involved in cancer services, have been put under over the past two years as a result of COVID-19 is fully recognised, which has served to increase pressure on an already stretched workforce. Creating a sustainable workforce to care for those with a cancer diagnosis must be an integral part of the Cancer Strategy.

Oncology and haematology services were fragile pre-COVID-19 with services often dependent on small teams and, in some instances, single-handed consultant practice. Multidisciplinary team work is an essential component of cancer care involving a wide range of health and social care professionals across both primary and secondary care. There is, however, unequal provision across cancer sites and across Trusts.

Diagnostic services are the first step in confirming a cancer diagnosis. There is currently a UK-wide shortage of radiologists which has an impact on the timeliness of investigations and results. Endoscopy services are under extreme pressure across all Trusts and are struggling to meet the growing demand. Likewise pathology services continue to struggle with increasing demand which has been compounded by the COVID-19 pandemic. There is particular concern regarding Medical Physics Expert provision which will have implications for the delivery of diagnostic services, radiotherapy, clinical trials and nuclear medicine in the near future. Our ambition to improve diagnostic services and to diagnose more cancers earlier cannot happen without significant investment to modernise and develop the diagnostic workforce.

Oncology services workforce planning and modelling was undertaken as part of the Oncology Services Transformation work in 2019. A blueprint was developed for a range of roles including nursing, pharmacy, therapy radiographers and doctors. The implementation of this plan is not progressing as planned due to funding constraints and, as a priority, must be implemented in full. If we are to ensure sustainability of services for the future a similar workforce plan must be developed for haematology as a matter of urgency.

Looking forward, the role of genomic medicine will have a significant impact on how we deliver cancer care. This will require a substantial increase in clinical scientist expertise.

Allied Health Professionals (AHPs) are the third largest professional workforce in the HSC, with 13 distinct and unique disciplines. AHPs are integral to the delivery of cancer care across the entire pathway.[69] They are essential in diagnosing cancer, in the delivery of cancer treatment, supporting people through treatment, leading the delivery of prehabilitation and rehabilitation services, managing the long-term effects of treatment and providing palliative and end-of-life care.

Across Northern Ireland, there is inequity of provision across Trusts. Service provision lacks consistency, has been developed in an ad hoc manner and is not sustainable in the longer term. As the number of people being diagnosed and living with cancer increases there is an inevitable knock-on impact on the workloads of AHPs which needs to be addressed as part of future workforce planning to meet the growing demand.

The challenge that lies ahead cannot be underestimated. While workforce planning has been undertaken or is underway in some specialties or professional groups, there is a compelling need to review the multidisciplinary cancer workforce as a matter of urgency. The workforce has grown in recent years but growth has not kept pace with the exponential rise in demand for diagnosis, treatment and ongoing care.

Over the past decade, there have been many major new developments in diagnosing and treating cancer including PET scanning, cytosponge, proton beam radiotherapy, immunotherapy and robotic surgery. Changes in the provision of care, type of treatments and procedures all have an impact on the workforce required to deliver the service.

In addition to an anticipated increase in numbers of staff required, we must address the appropriate skill mix, career pathways, training and retention of staff across the wide range of professions essential for the delivery of cancer services. The current service model for oncology is largely delivered by medical consultants supported by a wide range of other health professionals. The Oncology Services Transformation Plan (2019) clearly demonstrated the need to move towards a consultant-led service, with more services delivered by advanced nurse and AHP practitioners, in line with best practice internationally.

As we move towards the new model, we need to be mindful of the lead-in time required to train and develop staff. It should also be noted that increasing the numbers of non-medical prescribers and advanced nurse and AHP practitioners is associated with a knock-on effect on medical consultants who will be tasked with providing training, mentorship and supervision.

With advances in treatment, many cancers are becoming long-term, chronic conditions; consequently, there is a growing need for the provision of more specialist care in a primary-care setting, closer to home, for suitable patients. New roles such as primary care oncology nurse specialists, specialist AHP

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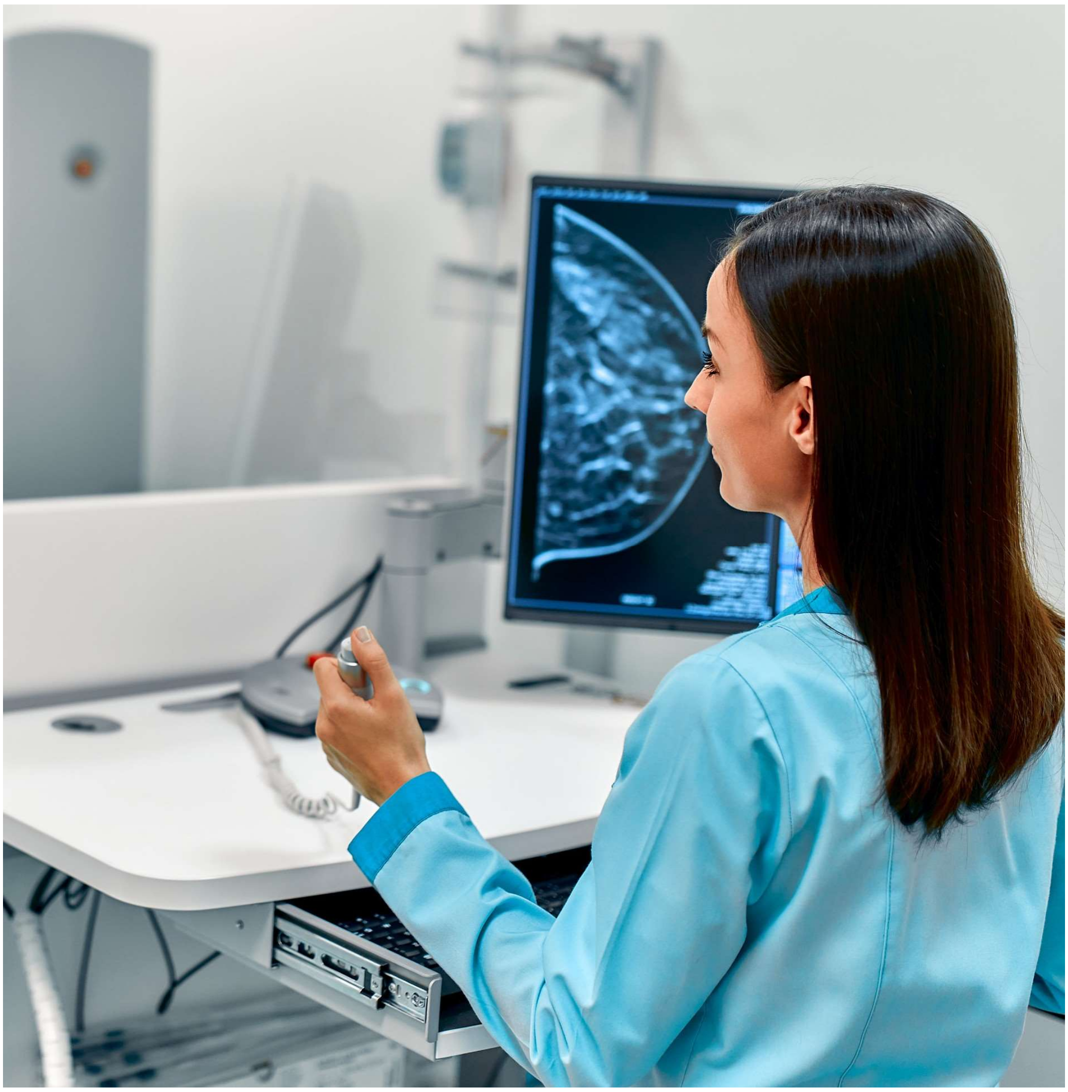
[69] NHS England (2018) 'Quick Guide: The role of allied health professionals in supporting people to live well with and beyond cancer. Transforming health, care and wellbeing with allied health professionals', London:Allied Health Professions team, https://www.england.nhs.uk/wp-content/uploads/2018/10/ quick-guide-ahp-cancer.pdf

practitioners and advanced nurse practitioners should be developed to work in the GP Federations.

Multi-professional education and training for staff at all levels and in all settings will be an essential enabler for the successful delivery of this plan. A comprehensive training programme must be developed and aligned with the new workforce plan adopting a regional approach to training. Our expectation is that multi-professional training should be the norm going forward.

Action 52. Develop a regional, multi-professional cancer workforce strategy and implementation plan. This will be underpinned by a training plan to ensure there are appropriately skilled staff to deliver services for the future.



Communicating with People Affected by Cancer

Communication lies at the heart of healthcare delivery. What people value most highly are good patient-professional interactions and being treated as a person. There is little doubt that communication between cancer patients and staff could be improved.

Breaking Bad News Regional Guidance For Northern Ireland was published in 2003.[70] This guidance outlines a pathway for medical and other professional staff to deliver bad news to patients, clients, their families and carers. Studies have consistently shown that the way a doctor or other health or social care professional delivers bad news places an indelible mark on the doctor/professional-patient relationship.

There is a specific challenge for parents who have been diagnosed with cancer in how best to communicate their diagnosis to dependent children,[71] with evidence highlighting a lack of support and guidance from healthcare professionals (HCPs). Most health care professionals (90%) have had no training in initiating and facilitating this parent-child communication.[72] This is also an issue for parents of children who have been diagnosed with cancer in how to communicate the information to siblings.

Action 53. All healthcare professionals who are expected to carry out sensitive communication must complete an advanced communication skills training programme.

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[70] DHSSPSNI (2003) 'Breaking Bad News Guidelines. DHSSPSNI', breaking_ bad_news.pdf (headandnecktrauma.org).

[71] Semple, C.J. & McCance, T. (2010) 'Parents' experience with cancer who have young children: A literature review', Cancer Nursing 33 (2) 110-118.

[72] Semple, C.J., McCaughan, E. & Smith, R. (2017) 'How education on managing parental cancer can improve family communication', Cancer Nursing Practice 16, 34-40.

Research

Within the health and social care sector, the provision of high-quality cancer care is a priority. Among all providers, there is a clear focus on the provision of person-centred services and on improving the experience of care. We know that participation in cancer research improves outcomes for people across all parts of the patient pathway. Research is not an add-on to the delivery of normal care, but it is foundational in the delivery of excellence.

Northern Ireland has a rich heritage in cancer research. Cancer research is conducted across a wide range of organisations including the Northern Ireland Cancer Registry, HSC Trusts, universities, cancer charities, the private sector, and not-for-profit organisations. It is funded from a variety of sources, but there is potential for better co-ordination across organisations and an opportunity to influence research priorities for the future.

The All Ireland Cancer Consortium (AICC) was set up in 1999 with the core aim of reducing cancer incidence and mortality on the island of Ireland through cross-border and transatlantic collaborations in cancer research and education. The AICC has a crucial role to play in the development and implementation of evidence-based outcomes for people affected by cancer in Northern Ireland and beyond.

It is inevitable that there will be many significant advances in technology and new treatments over the life of this strategy. The pace of change in all aspects of cancer means that we must have more agile systems in place to adopt new innovations in a timely manner.

For the successful delivery of this strategy, we must embed a culture in which data, research and intelligence are seen as core components for increasing public awareness, an improved uptake in screening, more efficient and timely diagnostic services, better treatment and care, and ultimately better outcomes for people living with cancer. It is paramount that we optimise the involvement of people affected by cancer in formulating and developing research proposals.

Clinical Trials / Clinical Research

Over the past decade, many successes can be celebrated when looking at the delivery of cancer clinical trials across Northern Ireland, yet the number of patients being offered and participating in cancer clinical trials remains well below that reported in other jurisdictions. It is widely accepted that cancer clinical trials are essential, not only to allow patients to access to new or novel treatments, but more importantly to attract and develop a world-class workforce.

Participation in clinical research ensures that patients have access to novel therapeutic agents or techniques, which may otherwise not be accessible to them. It has been demonstrated that people treated in centres with a strong culture of participation in clinical research have improved outcomes, attributable to care from a highly-motivated team, delivering high-quality protocol-driven care.[73] [74] [75]

Research also benefits individual clinicians, in terms of developing their professional knowledge and skills, and delivers organisational benefits for healthcare providers, both in terms of reputation and in revenue generation from commercial studies. In addition, participation in clinical and transitional research will ensure that cancer care will be improved for future generations of patients.

Data from the 2018 Cancer Patient Experience Survey[76] demonstrated a concerning differential between Northern Ireland and England with only 15% of Northern Ireland patients reporting that they had been asked about taking part in cancer research/clinical trials compared to 31% for England.

The Northern Ireland Cancer Trials Network (NICTN) exists to promote high-quality cancer care by supporting the delivery of clinical research across the Trusts. The NICTN delivers both large, late-phase clinical trials and early-phase studies, as well as supporting the development and delivery of investigator-initiated studies through its Research Management Service. In addition, NICTN provides support for the Belfast Experimental Cancer Medicine Centre (Belfast ECMC) in the delivery of early-phase and biomarker-driven clinical trials. Currently the vast majority of clinical trial activity occurs within the Northern Ireland Cancer Centre in Belfast HSC Trust.

Participation in clinical trials is considered to be an important factor in the higher survival rates seen in childhood cancers, where around two-thirds of children are recruited onto trials. NICTN supports Teenager and Young Adults (TYA) trial activity when available, but activity in this area is extremely low. TYA trials either sit within paediatric or adult services with few straddling both. Going forward, it is important to ensure that trials for TYA are set-up locally in such a way that they can be supported through the transition between paediatric and adult services. In addition, stronger links should be developed with trial sites elsewhere in the UK and the Republic of Ireland.

The complex multidisciplinary nature of clinical trial delivery requires buy-in across Trusts with enhanced access to radiology, pathology and pharmacy services. The opening of trials continues to be challenged due to workforce

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[73] Majumdar, S.R., Roe, M.T., Peterson, E.D., Chen, A.Y., Gibler, W.B., Armstrong, P.W. (2008) ‘Better outcomes for patients treated at hospitals that participate in clinical trials’, Arch Intern Med. 168(6): 657–62.

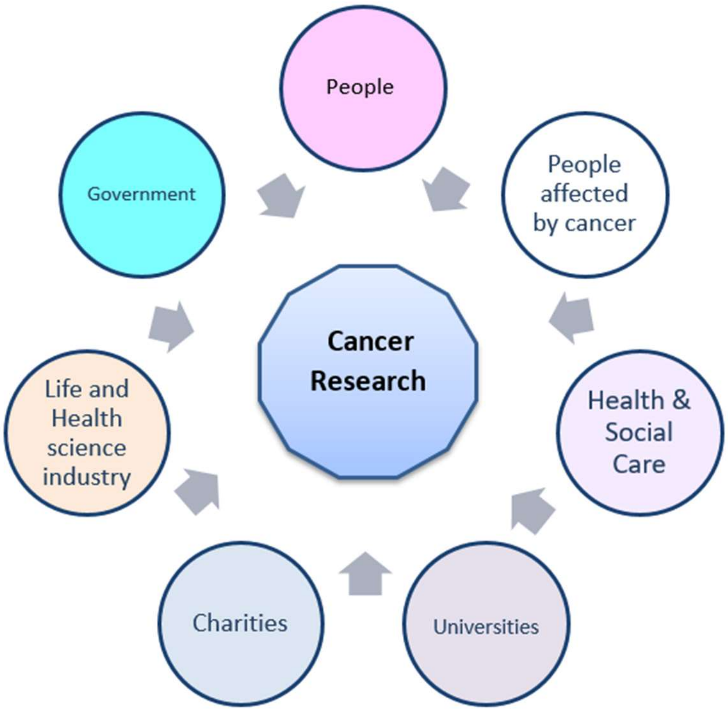
[74] Karjalainen, S., Palva, I. (1989) ‘Do treatment protocols improve end results? A study of survival of patients with multiple myeloma in Finland’, BMJ, 299(6707): 1069–72.

[75] Downing, A. et al. (2017) ‘High hospital research participation and improved colorectal cancer survival outcomes: A population-based study’, Gut, 66(1): 89–96

[76] HSC Public Health Agency (2018) ‘Northern Ireland Cancer Patient Experience Survey 2018’| https://www.publichealth.hscni.net/publications/northern-ireland-cancer-patient-experience-survey-2018

constraints including in terms of research nurses and medical physics experts. In addition, there is a need to ensure reliable funding streams and protected time within job plans to support clinical research across the region.

Figure 8: People with an interest in cancer research.



Per capita research spend in Northern Ireland is considerably lower than in the other UK nations.[77] [78] [79] [80]Numerous charitable organisations provide funding for NICTN activity but in the financial climate 'post-COVID' there is little doubt that this funding will reduce over the short to medium term. Sustainable funding on a par with the rest of the UK must be a key consideration in the ambition to provide better outcomes in the future.

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[77] National Institute for Health Research (2019) Annual Report 2019/2020 https://www.nihr.ac.uk/about-us/our-contribution-to-research/research-performance/12228_NIHR_Annual_Report_18_19.pdf

[78] Welsh Government (2020) 'Explore the Welsh Government's Final Budget 2020-2021' https://research.senedd.wales/research-articles/explore-the-welsh-government-s-final-budget-2020-21/.

[79] Scottish Government, Chief Scientist Office (2018) 'Health Research Board Annual Report' https://www.cso.scot.nhs.uk/wp-content/uploads/CSO1819OTsummary.pdf
39.https://www.hrb.ie/fileadmin/2._Plugin_related_files/Publications/2019_Publication_files/Health_Research_Board_Annual_Report_2018.pdf.

[80] Health Research Board, 'Annual Report' https://www.hrb.ie/fileadmin/2._Plugin_related_files/Publications/2019_Publication_files/Health_Research_ Board_Annual_Report_2018.pdf.

Understanding the Experience of People Living with Cancer

The ambition for cancer services must be to put people's experience and quality of life on a par with other clinical outcomes such as survival.

Ongoing information and research from patient groups, third-sector organisations and data from service user feedback systems such as Care Opinion and 10,000 Voices is invaluable in highlighting the experience of people living with cancer. There is, however, a recognised lack of information on the impact of treatment and long-term effects on people's lives. This reflects the lack of simple mechanisms by which patient-related outcomes and experience measures can be digitally gleaned and added to clinical records. Reliance on questionnaires, delivered separately or not directly linked to care delivery is inadequate.

At a population level in Northern Ireland, the only tool currently used to measure patient experience is the Cancer Patient Experience Survey (CPES). This has been carried out twice over recent years and both surveys have reported high levels of satisfaction with over 90% of people reporting their care as excellent or very good. CPES provides insight into the experience of people living with cancer locally and can be benchmarked with similar studies elsewhere in the UK.

The methodology is reliant on participants being willing and able to take part, and as a result, people with less survivable cancers, and those from more marginalised communities tend to be poorly represented. To date, the inclusion criteria is for those over 18 years of age. Consideration must therefore be given to how the experience of younger people can be measured. Recently, NHS England have worked with the Picker Institute to carry out the first CPES for under 16s. Learning from this work will be invaluable in shaping how the experience of children and young people in Northern Ireland is measured.

Patient Reported Outcome Measures (PROMs) represent a more person-centred approach to capture and address unmet supportive care needs. While interest exists in PROMS within clinical practice, there is no consistency in the tools or approach taken. The Scottish Cancer Recovery Plan (2020) has committed to provide national support to assessing the potential and value of digital PROMs. Learning from this will be invaluable going forward. In addition, NHS England has committed to the introduction of an innovative quality-of-life metric to track and respond to the long-term impact of cancer. When available, consideration should be given to adopting this for use in Northern Ireland.

Action 54. **Measure the experience of all people with cancer on an ongoing basis to inform service improvement and redesign.**

Action 55. **Develop a cancer research strategy for Northern Ireland in partnership with key stakeholders.**

Action 56. **Increase the number of people taking part in clinical trials, including children and young people.**

Data

Cancer can affect all aspects of a person’s life, therefore the information we collect is crucial to understanding how the delivery of services can be improved for the future.

The Northern Ireland Cancer Registry (NICR) is located in the Centre for Public Health, Queen’s University Belfast and is funded by the Public Health Agency for Northern Ireland. The registry was established in 1994 and a key function is the production of annual official statistics on cancer incidence, prevalence and survival in Northern Ireland. This includes data on screening, incidence and survival by age, sex, cancer type, variations due to deprivation, stage of disease, treatment and support services received.

The registry has expertise in the coding and analysis of healthcare data in cancerous and precancerous conditions. The level of knowledge within NICR is world leading, and with correct technology support and access to the live working systems of HSCNI their impact could be even greater.

Even with this expertise, Northern Ireland lags behind other UK nations in the range of cancer data it collects, ease of access to and use of the data that is collected. This has led to widespread frustration and dissatisfaction with the inability to link this information and to access routinely collected information from all of the available systems.

Accurate data is essential to underpin all decisions including, commissioning, service improvement and development, performance management and future planning. It is vital that common data sets are developed, agreed and used uniformly across the service.

The lack of routine prospective data collection of cancer treatments and outcomes in Northern Ireland makes assessment of the organisation and effectiveness of cancer services difficult. This highlights the need for routine data collection against the defined minimum datasets for cancer and submission to National Cancer Audits, to allow, not only benchmarking against cancer outcomes elsewhere in the UK, but also interpretation of local data on service provision required to inform and deliver service improvements.

Encompass/IT Systems

The new Encompass IT system is a critical part of the digital future of HSC. It will be transformational in its scope and will deliver a paper-less system in secondary care and enable much greater integration across acute and community services and social care. Encompass will replace many of the disparate systems in place currently and will add greater functionality.

It will also provide safe and protected individual data on the care provided with every clinical interaction coded in real-time by the care provider. A central component of Encompass is a patient portal, which will bring people closer to the care providers and will enable great transparency and communication between everyone involved in the care pathway.

The programme will start in South Eastern Trust in 2022 and roll out across Northern Ireland over the following two years. In the interim, there is a compelling need to develop and improve data systems which will be compatible with Encompass going forward.

Dedicated IT resources must be made available to support the implementation of this Strategy as we move towards cross-Trust working and a more digitally-enabled service.

Action 57. Review the data required for the effective delivery of cancer services in alignment with Encompass.

Action 58. Develop a cancer data framework to inform and improve cancer services and facilitate research.

Action 59. Review the Northern Ireland Cancer Registry.

Action 60. Make provisions to allow secondary use of data to allow benchmarking of Northern Ireland cancer outcomes across the UK.

Funding and Next Steps

The cancer pathway is complex and interfaces with all aspects of health and social care. Effective governance arrangements, combined with a focus on prevention, early diagnosis, evidenced-based treatment and support services are crucial, to ensure that the Strategy actions are implemented.

The Strategy provides the strategic direction and key steps to achieving the overall vision for improved cancer outcomes for the people of Northern Ireland. It presents a comprehensive and challenging programme of service stabilisation and improvement, reliant on collaborative working and new and innovative approaches to the delivery of care. Many of these require coordinated regional approaches and are likely to be challenging to achieve within the current service commissioning and Trust-based delivery structures. Delivery at this scale and speed will require investment in planning and project support infrastructures both within Trusts and across Clinical Networks, in particular the Northern Ireland Cancer Network (NICaN).

In order to meet these challenges, new governance structures will be established to performance manage and oversee the delivery of the Strategy. Strong clinical leadership and the inclusion of people with lived experience of cancer will be central to these structures.

As we move forward, it is also important that we acknowledge the difficult financial context in which this strategy is being issued. At the time of publication, all actions are subject to confirmation of funding and will therefore require prioritisation, workforce mapping and planning to ensure realistic delivery. The investment required to deliver the Strategy is significant, and is in addition to the existing expenditure in cancer services. It is not possible to fund implementation from within the Department’s existing resources and delivery is therefore dependent on the provisions of significant additional funding for the Department. Where it is possible, the Department will also seek to release resources through service efficiencies and reconfigurations; however, this in itself will not be sufficient to fund implementation. The pace of change outlined in this Strategy will also be considered in the context of other service priorities and with regard to the Department’s overall financial settlements.

In order for the delivery of the Strategy to be released over the next decade, collaboration and co-production will be crucial. This will involve maintaining and building on the many successful developments implemented over the past years in response to the pandemic, and learning from what could have been done better. Collaboration between HSC organisations, across sectors and with people affected by cancer including families and carers will be a key enabler to effecting meaningful change.

Appendices

Appendix 1: Cancer Strategy Actions

Action	Actions that can be fully or partially implemented without additional funding.[81]	Time to complete action after confirmation of funding and approval to initiate action.[82]
Theme 1 – Preventing Cancer		
1. Increase public awareness of cancer-related risk factors through specific strategies on tobacco, substance use, skin cancer prevention, and overweight and obesity – including diet and physical exercise.	Actions 1-4 are funded through other strategies. Work can commence without additional funding. It is expected these actions are continuous and will not have a completion date.	
2. Support the development and delivery of strategies to improve public health.		
3. Develop a co-ordinated approach towards chemoprevention in line with NICE recommendations.		
4. All people diagnosed with cancer must be offered appropriate and targeted information and support to live well.		
Theme 2 – Diagnosing and Treating Cancer		
5. Establish routes to diagnosis reporting and analysis on a regular basis to monitor changes to help improve diagnostic pathways and outcomes for patients.		12 months
6. Deliver regular, effective, targeted evidence-based 'Be Cancer Aware' campaigns harnessing the expertise in the community and voluntary sector.	This action is currently funded until 2024.	It is expected that this action will be ongoing.
7. Reduce sensitivity levels and extend the age range for the bowel screening programme.		The initial implementation project can be completed within 24 months. Implementation of services will take a further 18 months.
8. Implement HPV testing in the cervical screening programme.	Some project work is underway and the action can be partially completed in 12 months.	The action is expected to be completed in 3 phases. Full completion of the project – 12 months. Full roll out of training – 18 months.

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[81] Timelines for actions that can be fully or partially implemented without additional funding start at the publication of the Strategy.

[82] Not all actions can be completed simultaneously. The ability to start an action will depend on availability of funding and workforce. The time to implement the action is therefore from approval to initiate the action and not from the publication of the Strategy.

Action	Actions that can be fully or partially implemented without additional funding.[81]	Time to complete action after confirmation of funding and approval to initiate action.[82]
		Implementation of service – 18 months.
9. Increase uptake of all cancer screening programmes.	See action 6.	
10. Implement all UK National Screening Committee recommendations.		The extent and nature of this action depends on recommendations from the national screening programme and will be subject to confirmation.
11. Create surveillance systems for conditions where there is clear evidence regarding the pre-malignant potential of a particular condition to ensure people are not lost to follow up.		12 months
12. Implement NICE guidance including NG12, and in the future, the most current NICE referral guidelines.		Implementation projects – 18 months. Service delivery will be dependent on workforce and is not expected in the first three to five years of the Strategy.
13. A 28-day standard will be introduced to track the time for all people from first referral for suspected cancer to confirmation of a cancer diagnosis, which includes all diagnostic and staging investigations.		This action is not expected to be initiated in the first 3 years of the Strategy.
14. Review current targets to ensure equity across the pathway.		12 months.
15.Develop new pathways and diagnostic services to improve diagnosis.	Planning work underway – to be completed within 12 months.	18 months, subject to unexpected outcomes of the planning project.
16. Develop a specialist integrated haematological diagnostics service for Northern Ireland.	Initial work underway, with partial completion at 12 months.	Full service within 12 months.
17. Develop and implement prehabilitation and rehabilitation services on a regional basis for all those who will benefit.	Initial work underway funded by charities.	It is not expected that full implementation will be initiated in the first 3 years of the Strategy.
18. Reconfigure cancer surgical services alongside any future recommendations for the delivery of emergency and elective surgery.	Work is underway across other policies to consider future service structures.	Implementation need is unknown until outcome of other work.
19. Implement Enhanced Recovery After Surgery programmes on a regional basis for all appropriate major cancer surgery.		It is not expected that full implementation will be initiated in the first 3 years of the Strategy.

Action	Actions that can be fully or partially implemented without additional funding.[81]	Time to complete action after confirmation of funding and approval to initiate action.[82]
20. Introduce and implement new radiotherapy techniques and technology in line with national guidance including staffing and associated training.		24 months. Implementation will be continuous.
21. Implement in full the recommendations of the Oncology Service Transformation Project and the Oncology Haematology stabilisation plan.	This action is ongoing.	Further improvements within 6m of funding. Full completion is expected to take up to 4 years.
22. Ensure timely treatment where services cannot be provided in Northern Ireland due to the specialist nature of services, technology constraints or low number of patients. Continue to monitor the viability of providing these services locally including CAR-T.	Partial completion – 18 months.	24 months
23. Develop near-to-home phlebotomy services.	Partial completion – 12 months.	12 months
24. Review our model of delivery for Systemic Anti-Cancer Treatment Services including the delivery of near/close-to-home SACT.		12 months
25. Develop a 24/7 metastatic spinal cord compression service with rapid access to imaging and treatment.		12 months
26. Extend the acute oncology service across all Trusts to seven day working.		12 months
27. Deliver genetic and genomic testing in cancer pathways in line with NICE recommendations.	Ongoing through other strategies. 24 months.	
28. Develop ambulatory care haematology units in each of the Trusts and establish near-to-home treatment services for suitable patients.		12 months
29. Implement a safe and robust electronic prescribing system for all Systemic Anti-Cancer Treatment regimes.		Initial project – 12 months. Service delivery – 12 months after project.
30. Develop appropriate pathways and accessible services for older people with cancer, adults with learning disabilities, communication needs and chronic mental health problems, rarer cancers and metastatic cancer.	This action is part funded and can be scaled. Partial completion – 18 months.	Full completion – 18 months
31. Every child, young person and adult diagnosed with cancer, and their carers, will have access to staff with the specialist knowledge and skills to provide developmentally appropriate, person-centred care.	See action 52. Partial implementation - 18 months.	

Action	Actions that can be fully or partially implemented without additional funding.[81]	Time to complete action after confirmation of funding and approval to initiate action.[82]
32. Increase collaboration between Northern Ireland, Great Britain and the Republic of Ireland in the provision of children's oncology services.		18 months
33. Review the provision of services for teenagers and young adults in Northern Ireland including transition arrangements, age appropriate environments, psychological support and long-term follow up.		12 months
34. An effective multi-disciplinary team meeting will be held for all people diagnosed with cancer including cancer of unknown primary and metastatic disease.		12 months
Theme 3 – Supporting People to Live and Die Well		
35. Develop a person centred model of care that builds on learning from COVID-19 with increasing use of telehealth and technology.	Actions 35-37 and 42 are linked. Some work can be undertaken within existing funding. Partial completion – 12 months.	12 months
36. Offer all people a holistic needs assessment, an appropriate care plan and provide signposts to relevant sources of help and support.		
37. Develop a comprehensive treatment summary record for all people diagnosed with cancer.		
38. All people who have completed cancer treatment will be assessed and risk stratified to appropriate follow-up pathways.	Work ongoing. Partial completion – 18 months.	Project completion – 12 months Service implementation - 18 months after project depending on outcome of project.
39. All patients, including children and young people, diagnosed with cancer will have access to a Clinical Nurse Specialist throughout the entire care pathway.	Planning is ongoing. Partial completion – 12 months.	The action will be implemented on a phased approach. Implementation plan – 6 months enhanced training – 18 months full implementation – 5 years (depends on training and new/additional workforce)

Action	Actions that can be fully or partially implemented without additional funding.[81]	Time to complete action after confirmation of funding and approval to initiate action.[82]
40. In alignment with the mental health strategy, develop a model to promote good mental health and wellbeing for people affected by cancer, and develop pathways to ensure that all people with cancer have access to mental health support in line with their needs.	Pilots can be completed without additional funding - charity funding. Partial completion can be achieved on a phased approach: Start of pilot – 12 months. Evaluation – 24 months after pilot. Pathways – 18 months.	Full implementation 18 months after evaluation of pilots - depending on outcomes of pilots.
41. All people with a cancer diagnosis will be referred to a Cancer Information and Support Service at diagnosis.		12 months
42. Timely and appropriate access to therapeutic and practical support services for people affected by cancer targeting emotional, physical, spiritual and social needs will be provided.	See actions 35-37.	
43. All people starting cancer treatment will have their health status assessed and recorded and a plan developed to mitigate potential late effects and consequences of their treatment.	Actions 43-46 are combined. Initial work on service specification and pathways – 18 months.	Implementation is expected on a phased approach depending on outcomes of pathways. Completion of each phase – 6 – 12 months. The full completion is not expected for at least 7 years due to workforce pressures.
44. Develop a regional, multidisciplinary approach to the identification and management of all people at risk of late effects and consequences of their cancer treatment.		
45. Identify people deemed to be at highest risk for late cardiovascular effects and enrol them in a follow-up programme.		
46. Screen children to detect early, subtle cardiac abnormalities that might be treated, or may be reversible. In addition, where children are treated with anthracyclines or cardiac radiation they will have lifelong screening.		
47. Deliver integrated, coordinated and personalised palliative and end-of-life care to people with non-curative cancer when and where they need it.	Actions 47-51 are combined. Partial completion – 12 months	Full implementation – 5 years
48. All people with non-curative cancer will have access to a palliative care keyworker.		
49. Extend palliative and end-of-life support and continuity of care to seven		

Action	Actions that can be fully or partially implemented without additional funding.[81]	Time to complete action after confirmation of funding and approval to initiate action.[82]
day working for all people with non-curative cancer.		
50. Increase awareness and uptake of advance-care planning for all people with non-curative cancer.		
51. All people living with non-curative cancer, and those important to them, will have access to the bereavement, psychosocial and counselling support appropriate to their needs and preferences before and after death.		
Theme 4 – Implementing the Strategy		
52. Develop a regional, multi-professional cancer workforce strategy and implementation plan. This will be underpinned by a training plan to ensure there are appropriately-skilled staff to deliver services for the future.	Partial completion of new ways of working and structures – 12 months. Partial completion on workforce needs – 24 months.	Implementation will be ongoing.
53. All health care professionals who are expected to carry out sensitive communication must complete an advanced communication skills training programme.		12 months
54. Measure the experience of all people with cancer on an ongoing basis to inform service improvement and redesign.	Partial completion – 12 months	12 months
55. Develop a cancer research strategy for Northern Ireland in partnership with key stakeholders.	Partial completion – 18 months	18 months
56. Increase the number of people taking part in clinical trials, including children and young people.	Partial completion of project – 18 months	Project completion – 18 months. Service delivery – 36 months after project completion
57. Review the data required for the effective delivery of cancer services in alignment with Encompass.	Actions 57 and 58 are joined. Partial completion – 18 months	24 months
58. Develop a cancer data framework to inform and improve cancer services and facilitate research.		
59. Review the Northern Ireland Cancer Registry.	18 months	
60. Make provisions to allow secondary use of data to allow benchmarking of Northern Ireland cancer outcomes across the UK.		24 months

Appendix 2: Bibliography

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Appendix 3: Glossary of Terms

Age Standardised

The rates are calculated by applying the age-specific rates for the location being studied to a theoretical world-wide standard population, usually expressed per 100,000 persons per year.

Adjuvant Therapy

Another treatment used together with the primary treatment. Its purpose is to assist the primary treatment. Also called adjunctive or adjunct therapy.

Benign

Not cancerous. Benign tumours may grow but do not spread.

Brachytherapy

A type of radiation therapy where a radioactive source is placed in or near a cancerous tissue.

Cancer Incidence Rate

The number of new cancers of a specific site/type occurring in a specified population during a year.

Cancer Prevalence

The number of people now living who have ever been diagnosed with cancer. It includes people diagnosed with cancer in the past as well those who were recently diagnosed.

Clinical Nurse Specialist or CNS

A clinical nurse specialist (CNS) is a nurse specially trained to provide expert advice on treatment and care for a particular type of cancer.

Colposcopy

A procedure that allows a physician to take a closer look at a woman's cervix and vagina. It is used to check for precancerous or abnormal areas.

Cytosponge

A single-use device used to collect cells from the lining of the oesophagus. It is known as a 'sponge on a string' pill test. Cytosponge consists of a spherical spongein a dissolvable capsule, which is attached to a thread.

Digital pathology

This means that pathology samples can be shared and interpreted in the digital environment, so samples such as biopsies can be reviewed anywhere and it allows greater flexibility in how we utilise our pathology staffing.

Endoscopy

A nonsurgical procedure used to examine a person's digestive tract using a long, thin, flexible tube called an endoscope.

Genomics
A discipline in genetics that applies recombinant DNA, DNA sequencing methods, and bioinformatics to sequence, assemble, and analyse the function and structure of genomes (the complete set of DNA within a single cell of an organism).

qFIT or the Faecal Immunochemical Test
A stool test designed to identify possible signs of bowel disease. It detects minute amounts of blood in the faeces and can help to identify patients who may be at risk of bowel cancer.

Haematological malignancies
Types of blood cancers

Health and Social Care Board (HSCB)
A statutory organisation that arranges or ‘commissions’ health and social care services for the population of Northern Ireland.

Holistic Needs Assessment (HNA)
A questionnaire that enables professionals involved in supporting patients to understand all of the care and support needs a patient might have from concerns about their physical health through to issues around emotional, spiritual and social support.

HPV or Human papillomavirus
A virus that can cause cervical and other cancers.

Immunotherapy
A treatment which uses the immune system to fight cancer. It works by helping the immune system recognise and attack cancer cells.

Invasive cancer
Cancer that has spread beyond the layer of tissue in which it developed and is growing into surrounding, healthy tissues.

KPI or Key Performance Indicator
A quantifiable measure used to evaluate the success of an organisation, employee, etc. in meeting objectives for performance.

Metastatic Cancer
The spread of cancer from the primary site to other places in the body.

Molecular Diagnostics
A technique used to analyse biological markers in the individual’s genetic code in order to diagnose and monitor disease, detect risk, and decide which therapies will work best for individual patients.

Mortality rate
The number of deaths occurring in a specified population during a year, usually expressed as the number of deaths per 100,000 population.

Multidisciplinary teams
A group of healthcare workers who are members of different disciplines or professions each providing specific services to the patient.

Northern Ireland Cancer Network (NICaN)
This brings together Health and Social Care organisations, charities, cancer specialists and service users to improve cancer outcomes and experiences for patients.

Prehabilitation
The process of supporting patients to enhance their functional capacity or fitness ahead of treatment to enable them to cope with the treatment and to improve their outcomes after treatment.

Public Health Agency (PHA)
The major regional organisation for health protection and health and social wellbeing improvement.

Rapid diagnostic centres/hubs
These are designed to provide earlier and faster cancer diagnosis by providing a single point of access to diagnostic tests for all patients with symptoms that might suggest cancer.

Safety netting
This is about ensuring that there is a management system in place to ensure that patients receive the appropriate diagnostics and treatment in a timely way.

Stage of presentation
The stage at presentation describes the severity of a person's cancer based on the size and/or extent of the primary tumour and whether or not cancer has spread in the body.

Survival rate
The percentage of people in a study or treatment group who are alive for a given period of time after diagnosis.

Systemic Anti-Cancer Treatment (SACT)
The two main types of systemic therapy are chemotherapy (which uses drugs) and hormone therapy (which uses hormones). They can be given to increase long-term survival, control tumour growth and sometimes manage symptoms arising from the cancer.

Appendix 4: Abbreviations

ACE programme
Accelerate Coordinate Evaluate programme

ACP
Advance Care Planning

ADRT
Advance Decisions to Refuse Treatment

ADOG
All Departments Officials Group

AHP
Allied Health Professionals

AICC
The All Ireland Cancer Consortium

AOS
Acute Oncology Service

BAME
Black, Asian and minority ethnic

CAR-T
Chimeric Antigen Receptor T cell Therapy

CaPPS
Cancer Patient Pathway System

CCR
Cancer Care Review

COSD
Cancer Outcomes and Services Dataset

CPES
2018 Cancer Patient Experience Survey

CRUK
Cancer Research UK

DNACPR
Do Not Attempt Cardiopulmonary Resuscitation

CT scans
Computerised tomography scans

ERAS
Enhanced Recovery After Surgery

HDU
High dependency units

HNA
Holistic Needs Assessment

ICU
Intensive Care Unit

JCVI
Joint Committee on Vaccination and Immunisation

KPI or Key Performance Indicator

LINAC
A medical linear accelerator

LGBTQ+
Lesbian, gay, bisexual, and transgender queer and questioning

MRI Scan
Magnetic Resonance Imaging Scan

MSCC
Malignant spinal cord compression

MDMs
Multidisciplinary meetings

NCEPOD
National Confidential Enquiry into Patient Outcome and Death

NICaN
Northern Ireland Cancer Network

NCIN
National Cancer Intelligence Network

NICC
Northern Ireland Cancer Centre

NICTN
Northern Ireland Cancer Trials Network

NMSC
Non-melanoma skin cancer

NWCC
North West Cancer Centre

OST
Oncology Services Transformation Programme

PCiP
Palliative Care in Partnership programme

PET
Positron emission tomography

PROMs
Patient Reported Outcome Measures

PREMs
Patient Reported Experience Measures

PTC
Principle treatment centres

q-FIT
Faecal Immunochemical Test

SABR
Stereotactic Ablative Radiotherapy

TSR
Treatment Summary Records

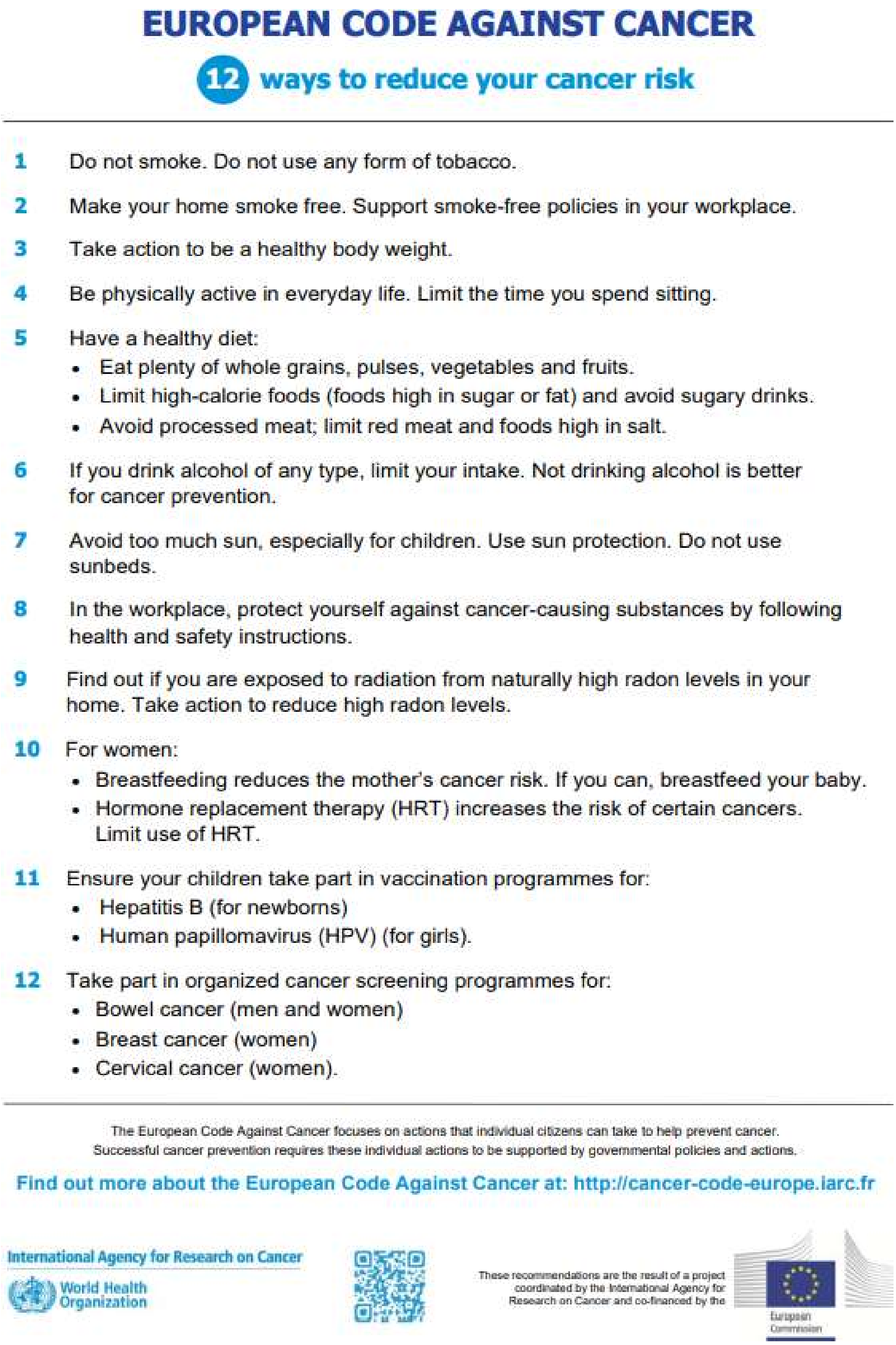
WHO
World Health Organisation

Appendix 5: Steering Group Members

Name	Organisation / Job Title
Charlotte McArdle	Chief Nursing Officer, Department of Health Chair
Brid Farrell	Public Health Agency, Public Health
Cathy Harrison	Chief Pharmacist, Department of Health
Dr Anna Gavin	Northern Ireland Cancer Registry
Dr Anne Kilgallen	Chief Executive Representative, Western Health & Social Care Trust
Dr Martin Eatock	Oncology, Belfast Health & Social Care Trust
Dr Miriam McCarthy/ Cara Anderson	Public Health Agency, Commissioning
Dr Naresh Chada	Deputy Chief Medical Officer, Department of Health
Dr Paul Molloy	General Practitioner Representative
Gay Ireland	Head of Cancer Policy/Cancer Strategy Project Manager, Department of Health
Heather Monteverde	Macmillan Cancer support/Chief Nursing Adviser, Department of Health
Ivan McMinn	Lived with experience/ Co-chair
Joan McEwan	Marie Curie
Joanne McClean	Public Health Agency, Paediatrics
Loretta Gribben	Public Health Agency, Nursing
Margaret Carr	Cancer Research UK
Mary Jo Thompson	Nurse Manager, South Eastern Health & Social Care Trust
Michael Bloomfield	Chair of Northern Ireland Cancer Network Board
Vivian McConvey	Patient Client Council

Appendix 6: Diagrams

Figure 9: European Code Against Cancer - 12 ways to reduce your cancer risk



EUROPEAN CODE AGAINST CANCER

12 ways to reduce your cancer risk

1. Do not smoke. Do not use any form of tobacco.
2. Make your home smoke free. Support smoke-free policies in your workplace.
3. Take action to be a healthy body weight.
4. Be physically active in everyday life. Limit the time you spend sitting.
5. Have a healthy diet:
    - Eat plenty of whole grains, pulses, vegetables and fruits.
    - Limit high-calorie foods (foods high in sugar or fat) and avoid sugary drinks.
    - Avoid processed meat; limit red meat and foods high in salt.
6. If you drink alcohol of any type, limit your intake. Not drinking alcohol is better for cancer prevention.
7. Avoid too much sun, especially for children. Use sun protection. Do not use sunbeds.
8. In the workplace, protect yourself against cancer-causing substances by following health and safety instructions.
9. Find out if you are exposed to radiation from naturally high radon levels in your home. Take action to reduce high radon levels.
10. For women:
    - Breastfeeding reduces the mother's cancer risk. If you can, breastfeed your baby.
    - Hormone replacement therapy (HRT) increases the risk of certain cancers. Limit use of HRT.
11. Ensure your children take part in vaccination programmes for:
    - Hepatitis B (for newborns)
    - Human papillomavirus (HPV) (for girls).
12. Take part in organized cancer screening programmes for:
    - Bowel cancer (men and women)
    - Breast cancer (women)
    - Cervical cancer (women).

The European Code Against Cancer focuses on actions that individual citizens can take to help prevent cancer.
Successful cancer prevention requires these individual actions to be supported by governmental policies and actions.

Find out more about the European Code Against Cancer at: http://cancer-code-europe.iarc.fr

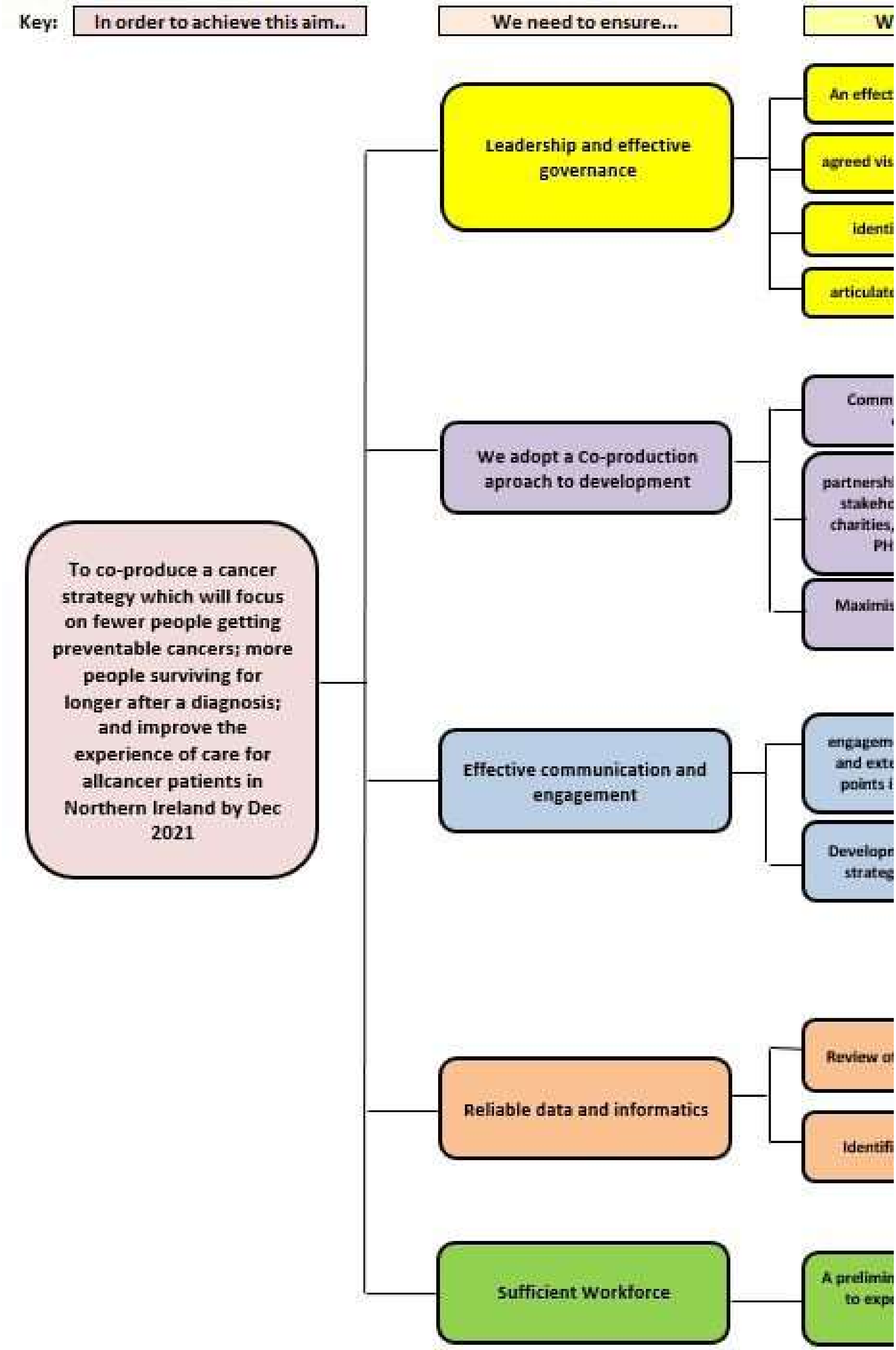
International Agency for Research on Cancer

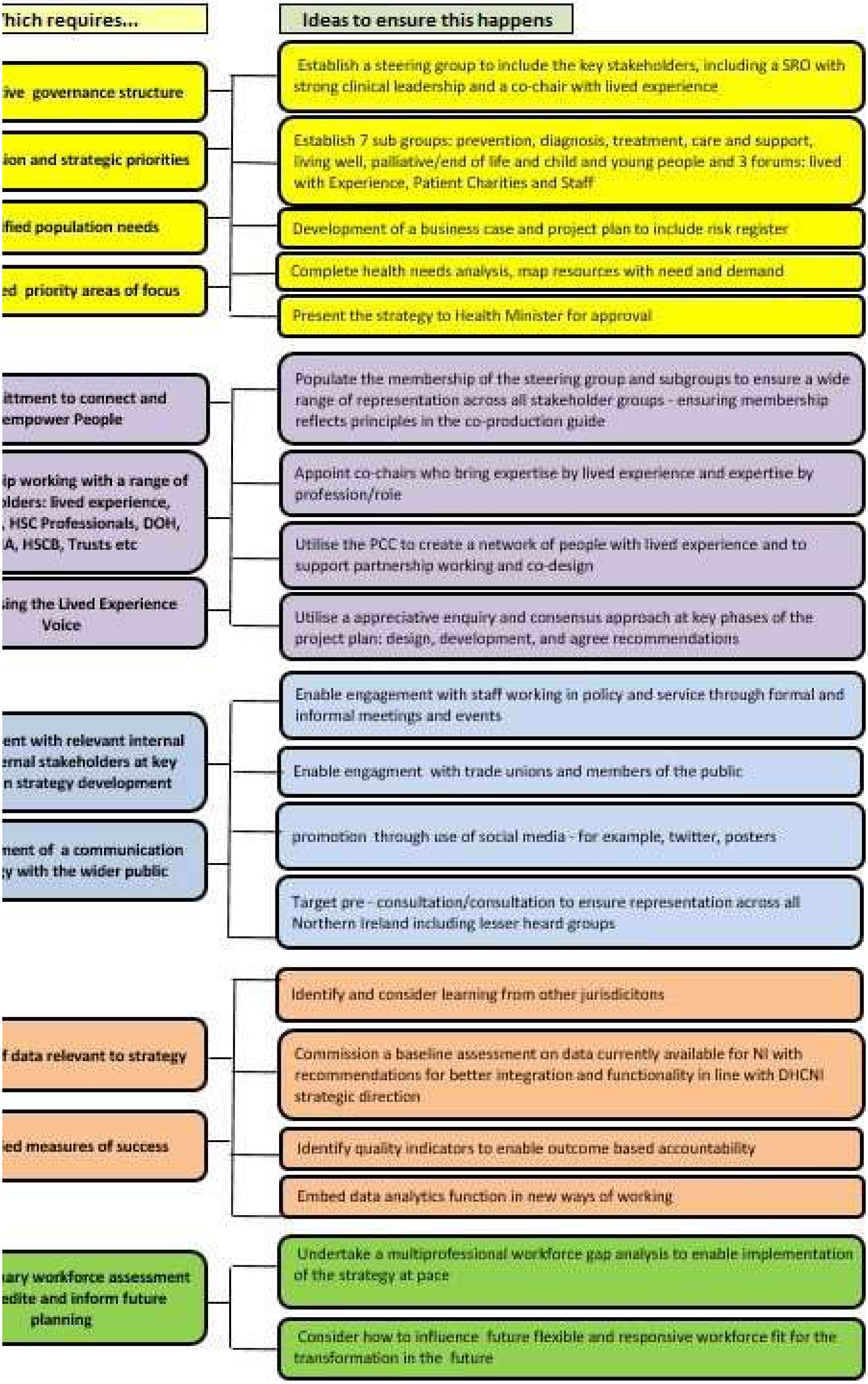
World Health Organization

These recommendations are the result of a project coordinated by the International Agency for Research on Cancer and co-financed by the

European Commission

Figure 10: Driver Diagram 1 - Developing the Strategy





hich requires...

Ideas to ensure this happens

ive governance structure

ion and strategic priorities

fied population needs

ed priority areas of focus

- Establish a steering group to include the key stakeholders, including a SRO with strong clinical leadership and a co-chair with lived experience
- Establish 7 sub groups: prevention, diagnosis, treatment, care and support, living well, palliative/end of life and child and young people and 3 forums: lived with Experience, Patient Charities and Staff
- Development of a business case and project plan to include risk register
- Complete health needs analysis, map resources with need and demand
- Present the strategy to Health Minister for approval

ittment to connect and empower People

ip working with a range of olders: lived experience, , HSC Professionals, DOH, A, HSCB, Trusts etc

sing the Lived Experience Voice

- Populate the membership of the steering group and subgroups to ensure a wide range of representation across all stakeholder groups - ensuring membership reflects principles in the co-production guide
- Appoint co-chairs who bring expertise by lived experience and expertise by profession/role
- Utilise the PCC to create a network of people with lived experience and to support partnership working and co-design
- Utilise a appreciative enquiry and consensus approach at key phases of the project plan: design, development, and agree recommendations

ent with relevant internal ernal stakeholders at key n strategy development

ment of a communication y with the wider public

- Enable engagement with staff working in policy and service through formal and informal meetings and events
- Enable engagment with trade unions and members of the public
- promotion through use of social media - for example, twitter, posters
- Target pre - consultation/consultation to ensure representation across all Northern Ireland including lesser heard groups

f data relevant to strategy

ed measures of success

- Identify and consider learning from other jurisdicitons
- Commission a baseline assessment on data currently available for NI with recommendations for better integration and functionality in line with DHCNI strategic direction
- Identify quality indicators to enable outcome based accountability
- Embed data analytics function in new ways of working

ary workforce assessment edite and inform future planning

- Undertake a multiprofessional workforce gap analysis to enable implementation of the strategy at pace
- Consider how to influence future flexible and responsive workforce fit for the transformation in the future