# **EQUALITY IMPACT ASSESSMENT**

# CANCER STRATEGY FOR NORTHERN IRELAND 2021-2031

# **Consultation Announcement**

This document is being presented as part of a full public consultation engagement exercise. It reports the outcome of a draft Equality Impact Assessment (EQIA) by the Department and comments are welcomed.

Requests for versions of the EQIA in accessible formats will also be considered. Consultation on the EQIA will end on the 17 November 2021.

We hope that you will find time to comment on this document.

# CONTACT

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# Accessibility statement

Any request for the document in another format or language will be considered.

# 1.0 Background

This Equality Impact Assessment is published alongside the full consultation document available at <a href="https://consultations.nidirect.gov.uk">https://consultations.nidirect.gov.uk</a>

# 1.1 What Is An Equality Impact Assessment?

Schedule 9 of the Northern Ireland Act 1998 provides for a comprehensive consideration by public authorities of the need to promote equality of opportunity, giving effect to Section 75 of the Act, between:

- People of different religious belief, political opinion, racial group, age, marital status or sexual orientation;
- Men and women generally;
- People with a disability and people without one; and
- People with dependants and people without dependants.

These are called 'Section 75 Groups' because the relevant law is Section 75 of the Northern Ireland Act 1998. In addition, without affecting the above duty, public authorities must have regard to the desirability of promoting good relations between people of different religious beliefs, political opinions and racial groups.

Equality Schemes must be prepared, which among other things must set out arrangements for assessing the likely impact on the promotion of equality of opportunity of the policies adopted or proposed.

Where equality impacts are likely to be major, a public authority needs to undertake an Equality Impact Assessment (EQIA). This is "a thorough and systematic analysis of a policy, whether the policy is written or unwritten, formal or informal, and irrespective of the scope of the policy or the size of the public authority."

As part of the assessment, consideration must be given to anything that could reduce any adverse impact on equality of opportunity of the policies proposed. Thinking through what opportunities exist to better promote equality must also be a part of the assessment. Consideration to alternative policies that might better promote equality of opportunity must also be given.

# 1.2 Policy Overview:

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 NI are diagnosed with cancer every day, and almost 10,000 people are diagnosed with cancer annually. The number of cancer cases diagnosed increased 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 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.

Despite efforts being made to reduce the growth in the incidence of preventable cancers in Northern Ireland (NI), there is evidence to suggest that the pace of change in reducing the risk factors underpinning these cancers is not sufficient.

Largely preventable cancers predicted to increase include melanoma and lung cancer. Ultimately, this highlights the real need to maintain focus on tackling preventable cancers, and the urgency for accelerating change.

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, 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 1- and 5-year survival rates between 2010-2014 for 4 of the 7 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 in Northern Ireland – 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.

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 NI 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.

# 1.3 Impacts on People and Scope of the Equality Impact Assessment

The EQIA shows that some equality groupings would be likely to have particular needs in relation to the Cancer Strategy and this is explored in this EQIA.

The total population in Northern Ireland, including people in the Section 75 categories, are expected to benefit from the proposals.

A series of People's Priority reports published by the Patient Client Council have highlighted that the delivery of quality cancer services are an ongoing priority for the population of Northern Ireland. The reports highlighted that:

"People who identified cancer services as a top priority were concerned about diagnosis, treatment and care of cancer, as well as access to cancer treatments, screening, aftercare, counselling, and working with cancer charities and voluntary organisations."

This has been further supported by the ongoing engagement with people with lived experience of cancer, carers and cancer charities as part of the co-production of the Cancer Strategy.

The aims of the strategy are threefold;

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

The overall aim to improve equality of access through regional initiatives will place Northern Ireland at the forefront of world class cancer prevention, treatment and patient experience. Any perceived negative impacts must be balanced with these potential benefits.

Longer term decisions on implementation of the recommendations have yet to be taken. Final decisions will be subject to further engagement and consultation at a local and regional level as required. Equality considerations must be set in this context.

# 1.4 Staff groups

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 year 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.

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 positron emission tomography (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 effective and efficient 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 Allied Health Professionals (AHP). We will develop and implement a regional, multiprofessional workforce plan to ensure we have the appropriately skilled staff available to deliver cancer services for the future. We will develop a regional, coordinated approach to training aligned with the workforce plan.

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.

Multiprofessional 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 must be aligned with the new workforce plan adopting a regional approach to training. Our expectation is that multiprofessional training should be the norm going forward.

Specific engagement with Trade Unions and staff groups will be a key focus during the implementation of the recommendations. Trusts, as employers, will have responsibilities to manage staff issues in line with best practice and pre-existing regional policies and agenda for change terms and conditions. These issues will be explored in detail through partnership working with staff groups and trade unions and human resource experts.

# 1.5 Scope Summary

This EQIA is concerned with the equality implications of the strategic policy direction with regards to actual and potential users of the service, their families and their carers. It also examines the impact on HSC staff.

A policy decision to implement regional initiatives for the delivery of cancer services may have an impact on certain groups. Similar impacts will exist irrespective of where these initiatives are developed in Northern Ireland.

Longer term decisions on implementation of the recommendations have yet to be taken. Final decisions will be subject to further engagement and consultation at a local and regional level as required. Equality considerations must be set in this context.

#### 2.0 Data Collection

In line with the Equality Commission (NI) Guide to the Statutory Duties and EQIA Guidelines, data was drawn from a number of sources to help us prepare this draft EQIA.

This EQIA is concerned with the equality implications of the recommendations set out in the Cancer Strategy, with regards to actual and potential users of the service and their carers. It also examines the impact on staff.

The Strategy has been developed using co-production methodology which has brought together people with lived experience of cancer and healthcare professionals from across all Health and Social Care Trusts (HSC), Public Health Agency (PHA), Health and Social Care Board (HSCB), Primary Care, policy makers and cancer charities.

In preparing this EQIA, the findings from a range of data and research sources were taken into account:

- Quantitative data (statistical information) to provide a first overview of the characteristics of those people most likely to be affected by the policy, including statistics from the Northern Ireland Statistics and Research Agency and the Northern Ireland Cancer Registry;
- Qualitative data gathered from research and academic literature also provides some insights into perceptions held by those who are likely to be most affected as well as suggestions for improvement.

The Strategy has also been influenced by a wide range of stakeholders during the co-production and pre-consultation phases of the strategy development. This included a series of meetings and workshops with people who have lived experience of cancer services in Northern Ireland in particular people with experience of palliative care, caring, and children, young people and local cancer charities.

During the full consultation period for this EQIA, the Department will continue to undertake engagement with a range of stakeholders as appropriate.

# 3.0 Key Findings

#### **Equality of Opportunity**

This section outlines our key findings across the nine equality groups outlined in Section 75(1) of the Northern Ireland Act:

- 1. Gender
- 2. Age
- 3. Religion
- 4. Political opinion
- 5. Marital Status
- 6. Dependant Status

- 7. Disability
- 8. Ethnicity
- 9. Sexual Orientation

#### 3.1 GENDER

#### **Service User Profile**

This strategy takes account of all cancers but focuses on the more serious, almost 10,000 per year, cancers which are a major cause of cancer deaths (excluding Non Melanoma Skin Cancer (NMSC)). 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.

Almost half (49%) of male and 42% of female cancer (ex. NMSC) patients had a comorbidity (other medical conditions) recorded up to one year prior to their diagnosis.

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 to 6,788 male and 7,450 female cases (excluding NMSC) is due primarily to population ageing.

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.

Some evidence suggests that women are more likely to have dependents/be a carer<sup>1</sup> than men and therefore this may have an impact, particularly if there is increased travel to attend appointments.

#### **Staff Profile**

In March 2020 seventy-nine per cent of staff (54,043) were female. Of these, 56% worked full-time. Of the remaining 14,723 male staff, 84% worked full-time. As above, some evidence suggests that women are more likely to have dependents/be a carer<sup>2</sup> than men and therefore the recommendations may have an impact on this group.

# **Potential Impact**

#### Service User

Women with dependants or caring responsibilities may be impacted, particularly if there are increased travel times associated with the implementation of the recommendations.

#### **Staff**

As the strategy is progressed there may be a change in how staff work, this may include working patterns, locations and the opportunity for skills development or retraining.

# Mitigation

<sup>1</sup> http://www.carersuk.org/images/News campaigns/CUK State of Caring 2019 Report.pdf

<sup>2</sup> http://www.carersuk.org/images/News campaigns/CUK State of Caring 2019 Report.pdf

Any potential negative impacts on specific groups will be offset by the benefits outlined in the strategy that aim to reduce the number of people diagnosed with preventable cancers, improving survival and improved experience of people diagnosed with cancer. This will include reduction in waiting times, thus reducing the impact on both physical and mental health.

A number of recommendations set out in Appendix 1 of the Cancer Strategy document outline how the strategy will use the next 10 years to focus on the patient journey through cancer services including preventing cancer, diagnosis and treatment of cancer and supporting people to live well and die well. There will be a continued focus on monitoring the prevalence of cancer by gender and cancer type to support clinically led decision making.

In the 2017/18 Health Survey for Northern Ireland, 79% of respondents indicated that, if they needed a routine procedure or operation they would be prepared to travel within Northern Ireland if it meant that waiting times would be reduced. 39% of respondents indicated that they would be prepared to travel up to 1hr to a hospital and 27% said up to 2hrs.

Throughout the development of the Strategy we have worked with people with lived experience of cancer services in Northern Ireland and their representative groups. The impact of the strategy on people with dependents and those living in rural areas has been considered, including access to services, access to travel either by public transport or private vehicle and scheduling of appointments at appropriate times. During COVID-19 many appointments moved from face to face to virtual and this has been welcomed by some, particularly in rural areas. Through the Strategy there will be increased opportunity for a more flexible approach to the delivery of services. This will be beneficial to patients and staff.

Prior to the pandemic many core services were fragile and struggling to deliver in a timely manner, with escalating waiting lists. We fully recognise the immense pressures the HSC, including all those involved in cancer services, has been put under over the past year as a result of COVID-19. Creating a sustainable workforce

to care for those with a cancer diagnosis is an integral part of this recovery plan and for the Cancer Strategy.

We will develop and implement a regional, multi-professional workforce plan to ensure we have the appropriately skilled staff available to deliver cancer services for the future. We will develop a regional, co-ordinated approach to training aligned with the workforce plan. This has the potential to create new opportunities and possible promotion and or skills development opportunities for staff.

These issues will be explored in detail through partnership working with staff groups and Trade Unions and human resource experts, during the implementation of the recommendations.

#### **3.2 AGE**

#### **Service User Profile**

Cancer is a disease related to ageing and increases in incidence in older adults. 2015 figures for 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. 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 co-morbidities, cognitive issues and complex social care needs.

The latest statistics for those waiting for a first consultant led outpatient appointment at 30<sup>th</sup> April 2021 in Northern Ireland identifies that 71.6% of the patients (64.7% Females and 78.0% Males) undergoing cancer treatment were over the age of 60.

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 socioeconomically deprived areas had overall cancer levels 15% higher than the NI 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 NI average overall, but higher levels of prostate cancer and melanoma.

Almost half (49%) of male and 42% of female cancer (ex. NMSC) patients had a comorbidity recorded up to one year prior to their diagnosis. Comorbidities (other medical conditions) are more common with age, can affect treatment options and affect survival, ranging at one year from 83.5% if no comorbidity, to 48.3% among those with at least four comorbidities recorded prior to diagnosis.

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 to 6,788 male and 7,450 female cases (excluding NMSC) 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.

Teenager and Young Adult 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.

The latest NISRA mid-year population estimates reported:

Northern Ireland population grows to 1.894 million in 2019 Northern Ireland's population (30 June 2019) was 1,893,700. The population increased by 12,000 people or 0,6 per cent between mid-2018 and mid-2019.

- Annual population change has remained positive over the last twenty five
  years. Growth has fluctuated from 0.1 per cent in 1999 to 1.1 percent in 2007.
  From mid-2018 to mid-2019 growth was 0.6 per cent. Over the last five years
  annual growth has remained at or around 0.6%.
- The ageing of the population from 2009 to 2019 is evident in the increasing population amongst the older ages. In the year to mid-2019, the number of people aged 65 or more increased by 2.1 per cent to 314,700 people.
- Last year, 1 in 6 people were aged 65 or more.

- The proportion of the population aged 65 or more has increased from 13.0 per cent in mid-1994 to 16.6 per cent in mid-2019.
- In contrast the proportion of the 2009 population aged 0 to 15 years has decreased from 25.4 per cent in mid-1994 to 20.9 per cent in mid 2019.

#### **Staff Profile**

Forty-one per cent of all staff were under the age of 40; 26% were between 40 and 49, and 33% were over 50<sup>3</sup>.

#### **Potential Impact**

#### **Service User**

A key outcome of this strategy must be improved experience for all people living with cancer in NI and in order to achieve this we need effective means of gathering the information. At a population level in NI 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 but has been postponed for 2021 due to the pandemic. CPES provides insight into the experience of people living with cancer locally and can be benchmarked with similar studies elsewhere in the UK. To date, the inclusion criteria is for those over 18 years of age. Consideration must therefore be given as to how the experience of younger people can be measured.

There is potential impact for people across the age spectrum in relation to specific needs associated with palliative care and pre bereavement and bereavement support. This should be a consideration when developing individual plans.

#### Staff

<sup>3</sup> https://www.health-ni.gov.uk/sites/default/files/publications/health/hscwc-march-19.pdf

If staff need to relocate or alter working patterns they may experience an increase in travel time and associated costs. This could lead to difficulties for staff with childcare, or other caring responsibilities, and to some older staff volunteering for early retirement. Younger staff who may be in a lower income bracket may experience difficulty meeting an increase in travelling costs or may have less access to public transport. Any increase in additional posts may create opportunities for staff.

Following the outcome of the public consultation, EQIA and Rural Needs assessment further consideration will be given to examining in greater detail the needs of all affected stakeholders including staff.

# Mitigation

Any potential negative impacts on specific groups will be offset by the benefits outlined in the strategy that aim to reduce the number of people diagnosed with preventable cancers, improving survival and improved experience of people diagnosed with cancer. This will include reduction in waiting times, thus reducing the impact on both physical and mental health.

A number of recommendations set out in Appendix 1 of the Cancer Strategy outlines how the strategy will use the next 10 years to focus on the patient journey through cancer services including preventing cancer, diagnosis and treatment of cancer and supporting people to live well and die well. There will be a continued focus on monitoring the prevalence of cancer by age and cancer type to support clinically lead decision making. This will be further supported by:

- The development of appropriate pathways and services for older people with cancer, rarer cancers, teenage and young adults and people seldom heard.
- Developing plans to ensure that every child diagnosed with cancer, and their carers, have access to staff with the specialist skills to provide holistic person centred care.

- Exploring the potential for greater collaboration between Northern Ireland,
   Great Britain and the Republic of Ireland in the provision of children's oncology services.
- Review the provision of services for teenage and young adults in NI including transition arrangements, age appropriate environments, psychosocial support and long term follow up.
- Develop methodology to measure the experience of those under 18 years of age.
- Arrange timely access for all people living with non-curative cancer, and those
  important to them, to the bereavement/psychosocial/counselling/chaplaincy
  services appropriate to their needs and preferences before and after death,
  across all care settings.

Prior to the pandemic many core services were fragile and struggling to deliver in a timely manner, with escalating waiting lists. We fully recognise the immense pressures the HSC, including all those involved in cancer services, has been put under over the past year as a result of COVID-19. Creating a sustainable workforce to care for those with a cancer diagnosis is an integral part of this recovery plan and for the Cancer Strategy.

We will develop and implement a regional, multi-professional workforce plan to ensure we have the appropriately skilled staff available to deliver cancer services for the future. We will develop a regional, co-ordinated approach to training aligned with the workforce plan.

These issues will be explored in detail through partnership working with staff groups and Trade Unions and human resource experts, during the implementation of the recommendations.

#### 3.3 RELIGION

#### **Service User Profile**

There is no qualitative or quantitative evidence available in relation to the religious beliefs of those individuals who are affected by cancer (cancer survivors, potential cancer patients and family, friends or carers of cancer survivors/patients).

# **Potential Impact**

The proposals will apply equally to all individuals irrespective of their religious belief.

#### 3.4 POLITICAL OPINION

#### Service User Profile

There is no qualitative or quantitative evidence available in relation to the political opinion of those individuals who are affected by cancer or use cancer services.

# **Potential Impact**

The proposals will apply equally to all individuals irrespective of their political opinion.

#### 3.5 MARITAL STATUS

#### **Service User Profile**

There is no qualitative or quantitative evidence available in relation to the marital status of those individuals who are affected by cancer or use cancer services.

#### **Potential Impact**

The proposals will apply equally to all individuals irrespective of their marital status.

# 3.6 DEPENDANT STATUS

#### Service user profile

Data is not collected specifically in respect of the carers of cancer patients in Northern Ireland.

However, Carers NI produced a report in November 2020 estimating there are currently over 360,000 carers in NI (whilst this data is useful as a reflection of the situation in Northern Ireland, it can't be guaranteed to be reflective of all carers in NI just those who respond to our surveys or YouGov polls)<sup>4</sup>. This notable increase is mainly due to the recent pandemic and people beginning to see themselves as carers as a result of shielding and bubbling.

Census data is available in respect of caring responsibilities of the NI population. In the 2011 Census respondents were asked whether they provided any unpaid help or support to family members, friends, neighbours or others because of long-term physical or mental ill-health/disabilities, or problems related to old age. Twelve per cent of the population (213,980) provided such unpaid care, around a quarter (26%) of whom did so for 50 or more hours a week, a total of 56,000 people. The information below shows the provision of unpaid care in Northern Ireland.

Care provided	<b>Count Percentage</b>	%
Provides no unpaid care	1,596,883	88.2
Provides 1-19 hours unpaid care per week	122,301	6.8
Provides 20-49 hours unpaid care per week	35,369	2.0
Provides 50+ hours unpaid care per week	56,310	3.1

<sup>&</sup>lt;sup>4</sup> https://www.carersuk.org/for-professionals/policy/policy-library/unseen-and-undervalued-the-value-of-unpaid-care-provided-to-date-during-the-covid-19-pandemic

Total 1,810,863 100Source: NISRA (2012) Table KS301 – Health and unpaid care (2011 numbers)

Based on information from Carers Northern Ireland (June 2011), the following facts relate to carers:

- 1 in every 8 adults is a carer;
- There are about 207,000 carers in Northern Ireland;
- One quarter of all carers provide over 50 hours of care per week;
- People providing high levels of care are twice as likely to be permanently sick or disabled as the average person;
- About 30,000 people in Northern Ireland care for more than one person; and
- 64% of carers are women; 36% are men.

In 2012, the Carers Trust estimated that around 49,000 carers in Northern Ireland were over the age of 60.

Between the 2001 and the 2011 Censuses there was an increase in the number of people providing unpaid care. In 2011, Carers NI estimated that by 2037 the number of carers could increase to 400,000.

Additionally, Carers UK carried out an online survey between March and May 2019. A total of 8,069 carers and former carers responded to the survey – 762 of whom were from Northern Ireland. Responses from the 694 people who are currently providing care were included in this report. Compared to the carer population as a whole, respondents to this survey were more likely to be female and caring for a high number of hours every week. Of respondents to the survey:

- 83% identify as female and 16% identify as male.
- 26% consider themselves to have a disability.
- Less than 1% are aged 0–24, 5% are aged 25–34, 16% are aged 35–44, 36% are aged 45–54, 28% are aged 55–64, 11% are aged 65–74, and 4% are aged 75 and over.
- 30% also have childcare responsibilities for a non-disabled child under 18.

- 57% are in paid work. Of those, 59% work full-time and 41% part-time.
- 32% have been caring for 15 years or more, 15% for between 10–14 years,
   24% for 5–9 years, 24% for 1–4 years, and just 4% have been caring for less than one year.
- 42% care for 90 or more hours every week, while 15% care for 50–89 hours,
   22% care for 20–49 hours, and 21% care for 1–19 hours a week.
- Most (66%) care for one person, 28% care for two people, 4% for three people, and 3% care for four or more people.

In November 2018, the Department published results from the Health Survey Northern Ireland First Results 2017/18.<sup>5</sup> Where over half of the carers (55%) received help from family members, while almost a third (32%) stated that they didn't receive help from anyone else. Almost three-quarters of carers (73%) received no money for their help. It also revealed that of the 3,355 interviews undertaken, 13% of respondents across all age groups (16+) indicated that they had caring responsibilities.<sup>6</sup>

In developing this Strategy we have engaged with people who have lived experience of cancer and carers from across Northern Ireland. They also highlighted the importance of flexible appointment times, especially for those travelling a greater distance and/or by public transport and for those with caring responsibilities.

#### Staff Profile

In March 2020 seventy-nine per cent of staff (54,043) were female. Of these, 56% worked full-time. Of the remaining 14,723 male staff, 84% worked full-time. As above, some evidence suggests that women are more likely to have dependants/be a carer<sup>7</sup> than men and therefore the recommendations may have an impact on this group.

<sup>&</sup>lt;sup>5</sup> https://www.health-ni.gov.uk/sites/default/files/publications/health/hsni-first-results-17-18.pdf

<sup>&</sup>lt;sup>6</sup> https://www.health-ni.gov.uk/sites/default/files/publications/health/hsni-first-results-17-18.pdf

<sup>&</sup>lt;sup>7</sup> http://www.carersuk.org/images/News campaigns/CUK State of Caring 2019 Report.pdf

#### **Potential Impacts**

#### Carers

Some groups of carers will have particular needs and issues in relation to reconfigured services:

- Age Younger and older carers tend to have less access to a car and rely more heavily on public transport than other age groups. The location of cancer services thus has particular implications for their ability to visit the person they care for. As so-called 'sandwich carers', those in middle age groups at times carry caring responsibilities for both children and elderly relatives. Longer travel times will negatively impact on their ability to juggle both sets of responsibilities.
- Ethnicity Black and minority ethnic carers often have less access to support from family and community networks. As support is sometimes highly localised they may be less able to draw on these networks if cancer services are located further away. Likewise, caring for their relative at home in general and a quicker discharge might pose greater challenges for them as they seek to prepare for the person returning home. Some individuals will face language barriers unless information and communication draws on interpreters and translations.
- Disability Some carers who themselves have a disability may face additional challenges in relation to care at home and an earlier discharge. Likewise, they are likely to have particular needs in relation to transport and location, similar to those outlined above under 'age'. Those with sensory impairments or a learning disability will have needs for information to be provided in an appropriate format and for communication to draw on appropriate support.
- Sexual Orientation For same-sex carers, a change in care setting and staff providing care to their partner is often associated with concerns about having

to 'come out' to a new group of staff yet again and about how their partner will be treated.

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

Those with a caring responsibility may have to attend appointments in relation to their own health, and/or accompany a dependant for an appointment. They may be impacted by additional travel times.

#### **Staff**

Staff relocating who have to travel further may experience difficulties in achieving a good work/life balance and may also incur additional care costs for children.

# Mitigation

Any potential negative impacts on specific groups will be offset by the benefits outlined in the strategy that aim to reduce the number of people diagnosed with preventable cancers, improving survival and improved experience of people diagnosed with cancer. This will include reduction in waiting times, thus reducing the impact on both physical and mental health.

A number of recommendations set out in Appendix 1 of the Cancer Strategy outlines how the strategy will use the next 10 years to focus on the patient journey through

cancer services including preventing cancer, diagnosis and treatment of cancer and supporting people to live well and die well. It is evident that carers play a vital role and provide significant support to people living with cancer at all stages, we will continue to engage directly with carers and their advocates to ensure their role is recognised, specifically the Strategy recommendations include:

- Ensuring that all health care professionals who are expected to carry out sensitive communication complete an advanced communication skills training programme.
- Ensuring that every child diagnosed with cancer, and their carers, have access to staff with the specialist skills to provide holistic person centred care.
- Supporting people and their carers to discuss their wishes and preferences for care at the end of life and that this is recorded in a shareable format with the relevant people.

We recognise the immense pressures the HSC, including all those involved in cancer services, has been put under over the past year as a result of COVID-19. Creating a sustainable workforce to care for those with a cancer diagnosis is an integral part of this recovery plan and for the Cancer Strategy.

We will develop and implement a regional, multi-professional workforce plan to ensure we have the appropriately skilled staff available to deliver cancer services for the future. We will develop a regional, co-ordinated approach to training aligned with the workforce plan.

These issues will be explored in detail through partnership working with staff groups and Trade Unions and human resource experts, during the implementation of the recommendations.

#### 3.7 DISABILITY

#### Service user profile

There is currently no specific data relating to disability and cancer gathered in Northern Ireland.

Research carried out by Macmillan in 2013 found that at least one in four people living with cancer face 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 is often poorly managed, disjointed and uncoordinated.

A report by the UK charity Jo's Cervical Cancer Trust, which surveyed 335 women with diverse physical disabilities and conditions, ranging from spinal muscular atrophy to cerebral palsy, found that a high proportion of respondents (63%) said that they had previously been unable to attend a cervical screening appointment because they could not access screening services or did not have the option for home visits. Moreover, nearly 40% stated that their general practice surgery did not provide wheelchair access, with just 1% of respondents reporting that their surgery provided a hoist. Approximately 13·9 million people in the UK are considered to have a disability, of whom 56% are women and most have impaired mobility. These findings are worrying in terms of equality of access to cancer care, especially in the context of global issues of overall health-care access for people with disabilities.

#### Population profile

At February 2021, there were 75,940 claimants of Disability Living Allowance, a fall of 4.0% (3,130) on a year earlier. In the same month, there were 153,680 Personal Independence Payment claims in payment<sup>8</sup>.

<sup>&</sup>lt;sup>8</sup> https://www.communities-ni.gov.uk/system/files/publications/communities/benefit-statistics-summary-feb-2021.pdf

The number of people with a limiting long standing illness or disability in 2017 is noted below for all of Northern Ireland and by Health and Social Care Trust (HSCT):

Limiting longstanding illness by Health & Social Care Trust

	2019/20				
HSCT	%	Unweighted base	95% confidence intervals		
Belfast	32%	747	29. 0	to	35.7
Northern	31%	1028	28.0	to	33.6
South Eastern	31%	816	27.4	to	33.7
Southern	26%	881	23.3	to	29.1
Western	34%	613	30.0	to	37.5
Total	30%	4085	29.0	to	31.8

Source: Health Survey Northern Ireland

Respondents aged 16+

Census figures show that in 2011 just over one in five of the resident population (21%) had a long-term health problem or disability that limited their day-to-day activities. Strabane and Belfast (both 24%) had the highest proportions of residents with a long-term health problem or disability.

Disability  Long-term health problem or disability: limited a	Count Percent a lot 215,232	% 11.9			
Long-term health problem or disability: limited a	•	8.8			
Long-term health problem or disability: not limit	·	7 79.3			
Source: NISRA (2012) Table KS301 – Health and unpaid care					

According to a NISRA survey carried out in 2006; some 37% of households include at least one person with a disability and 20% of these include more than one disabled person.

For both men and women, the rate of disability increases with age. Women on average live longer than men therefore disability tends to be more common among women. The rate is particularly high for women aged 75 and above (at 62%). It is only among the youngest adults aged 16 to 25 that the rate for men (at 6%) is higher than for women (4%) (Northern Ireland Survey of Activity Limitation and Disability (2006/07).

Some 25% of the 3,780 adults receiving direct payments from their local Health and Social Care Trust have a physical or sensory disability (October – December 2018)<sup>9</sup>.

In Northern Ireland there are about 16,500 people with a learning disability; this is predicted to increase by 20.5% by 2021<sup>10</sup>. Any change to older people's services must take account of the needs of older people with learning disabilities as well as other forms of disability.

Type of long – term condition	% of population
Deafness or partial hearing loss	5.14
Blindness or partial sight loss	1.7
Communication Difficulty	1.65
Mobility of Dexterity Difficulty	11.44
Learning, intellectual, social or behavioural difficulty	2.22
Emotional, psychological or mental health condition	5.83
Long – term pain or discomfort	10.10
Shortness of breath or difficulty breathing	8.72
Frequent confusion or memory loss	1.97
A chronic illness (such as cancer, HIV, diabetes, heart diseas	se) 6.55

Source: Census 2011

# Staff profile

There is no specific data available on the profile of the HSC workforce relating to disability.

NHS England has commissioned a primarily quantitative research project<sup>11</sup>, focusing on the experiences of staff with disabilities working within the NHS, drawing upon two national data sets:

<sup>&</sup>lt;sup>9</sup> https://www.health-ni.gov.uk/publications/quarterly-direct-payments-statistics-december-2018

<sup>&</sup>lt;sup>10</sup> McConkey et al, (2006) Accessibility of healthcare information for people with a learning disability. A Review and Discussion Paper

<sup>&</sup>lt;sup>11</sup> Research on the experience of staff with disabilities within the NHS workforce - Middlesex University Research Repository (mdx.ac.uk)

- The 2014 NHS staff survey, completed by 255,000 staff, reporting their experiences of working in the NHS;
- The Electronic Staff Record (ESR), comprising data on the entire NHS workforce, gathered for workforce planning, personnel and wage payment purposes.

Key findings reported that staff with disabilities' representation at all levels of the NHS and covering different types of disability. Levels of reported disability are around 17% in the NHS Staff survey, and around 3% in the ESR. Neither data set allows for more specific analysis between different types or degrees of disability. The most likely reasons for the disparity between reported levels of disability are:

- 1. Differences in definition of disability used in the two data sets
- 2. Differing conditions for self-disclosure (NHS staff survey is anonymous)
- 3. Time of disclosure (ESR reports disability at the time of staff appointment, and is not reliably updated).

# **Potential Impact**

#### Service users

Service users with disabilities may have particular needs in relation to the way cancer services are organised, including:

- information and communication support needs (people with sensory impairments and those with a learning disability);
- specific transport needs (people with mobility impairments); and
- specific needs relating to the continuity of care, minimising the number of moves and changes in both the location and teams providing care (people with dementia).

#### Staff

Staff with a disability may experience issues relating to reasonable adjustments and attitudes of new colleagues.

Staff relocating to a new building may experience changes to their home to work journeys. If travelling by public transport there may be an adverse impact if the public transport services available to the new location are not adequate.

Staff travelling to work by car may be adversely affected if their current location provides disabled parking facilities and these are not available at the new location<sup>12</sup>.

# Mitigation

For those with learning difficulties and other communication issues including dementia it most often falls to carers, family or other health care 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. The Strategy aims to:

- Support better collaborative working between cancer services, learning disability and mental health services to improve outcomes for these groups of people.
- Provide appropriate information resources.
- Provide accessible formats for people to access information including technology, audio, and easy read.
- Consider options on better data collection on disability, co-morbidities and consequences of cancer treatment.

<sup>12</sup> 

Staff with disabilities may be affected by workplace related considerations and travel. Reasonable adjustments will be made concerning existing and newly appointed staff in the workplace. Some staff with disabilities may be asked to consider relocating from their current workplace.

#### 3.8 ETHNICITY

There is no qualitative or quantitative evidence available in relation to the ethnicity of those individuals who use or work in cancer services.

Since the 2001 Census, there has been a marked change in Northern Ireland's ethnic diversity. On Census Day 2011, 1.8% (32,400) of the resident population belonged to minority ethnic groups, more than double the proportion in 2001 (0.8%). The main minority ethnic groups were Chinese (6,300 people), Indian (6,200), Mixed (6,000) and Other Asian (5,000), each accounting for around 0.3% of the population. A census took place in March 2021 and data will be updated accordingly when published.

Cancer Registry have been informed that ethnicity is poorly recorded on HSCNI systems. Data from the NICR is benchmarked annually against the other registries in England, Scotland, Wales and the Republic of Ireland, and Ethnicity is one of the measures included in the KPIs. NI has been consistently zero whilst England reports 95% completeness. Going forward we suggest that this is a mandatory data field to capture this information.

While there is no local evidence of the incidence of cancer across the travelling community, UK research has been carried out regarding this area (Condon et al. BMC Public Health<sup>13</sup>).

<sup>&</sup>lt;sup>13</sup> Knowledge and experience of cancer prevention and screening among Gypsies, Roma and Travellers: a participatory qualitative study (biomedcentral.com)

Peer researchers conducted interviews (n = 37) and a focus group (n = 4) with a purposive sample of community members in Wales and South-West England. Participants self-identified as Roma (from Slovakia and Romania) or as Gypsies, Travellers or Showpeople (here described as Gypsy/Travellers). A third of the sample were Roma, and a quarter male, with ages ranging from 18 to 77 years. Data were collected from October 2018 to March 2019. Results reflected that women and men knew that lifestyle factors, such as healthy diet, stopping smoking, drinking less alcohol and using sun protection, contribute to cancer risk reduction. However, there was a widespread lack of confidence in the effectiveness of these measures, particularly in relation to smoking.

Traditional cultural beliefs were shared by Roma and Gypsy/Travellers, but did not necessarily affect the behaviour of individuals. Most women participated in cervical and breast screening but few Gypsy/Traveller men would engage with bowel screening, which conflicted with community ideals of stoical masculinity. Roma participants described language barriers to screening, with confusion about differences in timing and eligibility between the UK and Slovakian programmes; this led some to access screening abroad.

Conclusion: This study provides new knowledge about how Gypsies, Roma and Travellers keep healthy and prevent disease, giving insights into similarities and differences between ages, sexes and communities. These culturally distinct and high-need ethnic minorities have specific needs in relation to cancer prevention and screening, which merit targeted and acceptable health promotion to reduce health inequalities.

# **Potential impact**

Some minority ethnic individuals will not be fluent in English. The number of requests received by the Northern Ireland Health and Social Care Interpreting Service has risen from 63,868 in 2011/12 to 132,434 in 2019/20 showing the increasing demand on services responding to a greater diversity in the population.

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.

Ethnic Minority populations are less likely to have a car and rely more on public transport. Irregular public transport, combined with prolonged travelling times, can therefore represent a further barrier to accessing health care for ethnic minority patients<sup>14</sup>

Getting to hospitals is particularly difficult for people without a car or who are living in places with inadequate public transport options.

Ethnic Minority groups may experience communication barriers in accessing health care. This applies across health and social care.

#### Staff

Staff who are required to relocate may subsequently experience direct/indirect discrimination if the new location is less diverse.

# Mitigation

Any potential negative impacts on specific groups will be offset by the benefits outlined in the strategy that aim to reduce the number of people diagnosed with preventable cancers, improving survival and improved experience of people diagnosed with cancer. This will include reduction in waiting times, thus reducing the impact on both physical and mental health.

<sup>&</sup>lt;sup>14</sup> Potential barriers to the use of health services among ethnic minorities: a review □ Family Practice, Volume 23, Issue 3, 1 June 2006, Pages 325–348, https://doi.org/10.1093/fampra/cmi113 Family Practice, Volume 23, Issue 3, 1 June 2006, Pages 325–348, https://doi.org/10.1093/fampra/cmi113

A number of recommendations set out in Appendix 1 of the Cancer Strategy document outline how the strategy will use the next 10 years to focus on the patient journey through cancer services including preventing cancer, diagnosis and treatment of cancer and supporting people to live well and die well. To provide better access to information for people from ethnically diverse backgrounds the Strategy will support:

- Awareness raising campaigns co-produced with people from ethnically diverse backgrounds and their advocates. These will be specifically tailored to be more easily understood.
- Consideration on the translation of resources into other languages and to the provision of appropriate resources for those people with sensory impairment.
- Working in partnership with cancer charities which have a focus on promoting awareness and have developed resources in accessible formats.
- Data capture and evaluation are essential in order to measure impact and to learn and adapt campaigns for the future.

# 3.9 SEXUAL ORIENTATION

#### Service User Profile

Accurate figures are not available on the sexual orientation of the general population, neither is this information available for cancer survivors and potential cancer patients and estimates vary considerably.

#### **Potential Impact**

Feedback to the Palliative and End of Life Care cancer strategy subgroup from people with lived experience – along with wider literature/evidence – illustrates that LGBTQ+ people may experience a number of barriers to care when they, or a loved one, are impacted by terminal illnesses, including non-curative cancer.

It was also suggested at this sub group that LGBTQ+ people may be reluctant to use

health and social care services, present late to them or forgo them entirely due to

fears around stigma and discrimination. This may manifest in a number of ways – from overt discrimination to more subtle issues, eg:

- Assumptions that patients are heterosexual and/or that their same-sex partner is a sibling or other relative, forcing LGBTQ+ people to choose between coming out to HSC professionals or concealing their identity;
- Exclusion of same-sex partners from decision making and consultation around their loved one's care because the relationship isn't recognised or acknowledged, or because they aren't considered to be the 'proper' next of kin; of challenges arising from the religious element of chaplaincy services and the views/attitudes toward LGBTQ+ relationships in some religious belief systems. It is important to note, however, that guidelines for chaplaincy services emphasise that chaplains are appointed for the care for all patients regardless of faith or life stance; it is not the suggestion of this paper that difference in treatment of LGBTQ+ people is a widespread phenomenon in chaplaincy services.

In the bereavement phase, evidence also highlights the disenfranchised grief experienced by some bereaved LGBTQ+ people, who may not be offered or receive the support they need if their relationship was hidden or not recognised or acknowledged.

Research [Marie Curie (2015). 'Hiding who I am': The reality of end of life care for LGBTQ+ people identifies a number of actions that can help to mitigate against these challenges, including:

- Use of LGBTQ+ imagery and symbols (e.g. the rainbow flag) and language inclusive of diverse groups in health and social care literature.
- Training for HSC staff and other service providers on the concerns and needs of LGBTQ+ people at the end of life.
- Promotion of language that is inclusive of the LGBTQ+ community throughout health and social care services.

#### Mitigation

While the proposals will apply equally to all individuals requiring cancer services irrespective of their sexual orientation it is recognised that there are specific issues in relation to sexual orientation that should be further considered. As the strategy is further developed we will work with key stakeholders to address issues in the delivery of cancer services.

A number of recommendations set out in Appendix 1 of the Cancer Strategy document outline how the strategy will use the next 10 years to focus on the patient journey through cancer services including preventing cancer, diagnosis and treatment of cancer and supporting people to live well and die well. To provide better access to information for people with different sexual orientation's the Strategy will:

 arrange equitable access to palliative and end of life support and continuity of care for all people with non-curative cancer 24 /7.

# 4.0 Disability Duties

Section 75 of the Northern Ireland Act 1998 and Section 49A of the Disability Discrimination Act 1995, require public authorities, including the Department of Health, to have due regard to:

- promote equality of opportunity between people with a disability and people without (Section 75)
- promote positive attitudes towards people with a disability (Section 49A)
- encourage the participation of people with a disability in public life (Section 49A)

This means that when carrying out their functions, such as when making decisions and policies and in setting their priorities, public authorities must give serious consideration to these three goals and consider taking suitable action to achieving them.

The Disability Discrimination Act 1995 bans disability discrimination by employers against jobseekers and employees with disabilities, and by service providers against service-users with disabilities.

It places a duty on employers and service providers to make reasonable adjustments for people with disabilities to help them to overcome barriers they may face in gaining and remaining in employment and in accessing and using goods and services.

#### 5.0 Good Relations

We have identified no major issues impacting on good relations.

# 6.0 Human Rights

The screening exercise highlighted that the Cancer Strategy has the potential to have a positive impact in relation to Article 2 – Right to life. All other Articles have been assessed as neutral impact.

#### 7.0 Conclusions

This EQIA had used available evidence to consider all 9 Equality groupings. It is evident that this proposed strategy may impact the groups below:

Gender

Age

**Dependant Status** 

Disability

**Sexual Orientation** 

This Draft EQIA highlights a range of mitigating actions that would address the inequalities identified. As part of the consultation process we invite stakeholders to

consider the information included within this Draft EQIA and associated consultation documents and provide feedback and relevant information to shape the strategy over the next 10 years. If you have any questions or would like to discuss this Draft EQIA please contact us at Cancer.Strategy.2020@health-ni.gov.uk.

# 8.0 Proposed Monitoring

Consultation responses will be identified and categorised, where possible, according to key Section 75 issues that may be highlighted.

Additional comments are welcomed specifically as they relate to this Draft EQIA will be asked in the consultation response questionnaire.

# 9.0 Co-Production and Involvement Processes

The development of the Cancer Strategy has meaningfully included service users and cares throughout.

# **Regional Structure**

The Cancer Strategy development is led by a Steering Group; this group is cochaired by a person with lived experience and a clinical professional. It has been meeting since June 2019. Steering Group membership includes representation from charities, lived experience people, subject experts in workforce, policy, primary care, secondary care and research and development.

The Steering Group is supported by seven sub-groups, which are also co-chaired by people with lived experience, these are: prevention; diagnosis; treatment; care and support; living well; palliative / end of life and children and young people. All sub-groups consider issues affecting patients across the full age range with particular focus on older people and accessibility as well as children and young people (16 to 24).

# **Co-Production planning group**

A group of people living with cancer has been established under the leadership of the lived experience co-chair of the Steering Group, sub-group co-chairs, DoH Policy Lead, HSC officials from Patient Client Council and Public Health Agency. The group facilitates input from people living with cancer and their carers in the development of the strategy by sense checking and feeding back to the steering group on output from the sub-groups.

# **Cancer Strategy Service User and Carer Reference Group**

A reference group has been established with 27 people with lived experience representing different geography, demographics and cancer specialities. This group was openly recruited via advertisement regionally through the PCC Make Change Together platform.

The group have participated across a range of activities, including an induction and regional workshop as well as providing specific feedback on the draft recommendations by speciality.

# **Engagement with Third Sector**

DoH are working directly with the NI Cancer Network (NICaN) with the aim of ensuring that we maximise input from those with experience of both delivering and using services right across the cancer journey. A series of meetings has taken place as part of on-going and pre-consultation engagement.