



Northern Ireland  
Assembly

## Research and Information Service Briefing Note

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# Cancer services: Northern Ireland and the Republic of Ireland

## 1. Introduction

This paper provides information in response to a Member's request regarding information on cancer services. As some of the financial data requested is unavailable, the paper focuses on cancer policies and services in Northern Ireland and the Republic of Ireland. It also explores the current level of cross-border collaboration in terms of cancer care and services.

## 2. Background: What is cancer?

Cancer is a group of diseases which occurs when abnormal cells in the body divide without control. As a result, normal cell growth is disrupted. Rather than replacing cells that have been damaged or lost, cancer cells multiply uncontrollably. This uncontrolled growth can cause a lump or tumour to form.<sup>1</sup> Sometimes these tumours are not cancerous. In such cases, they are called benign tumours.

- In contrast, when a tumour is made up of cancerous cells, it is described as **malignant**.

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<sup>1</sup> Cancer Research UK website 'What is cancer' <http://www.cancerresearchuk.org/cancer-help/about-cancer/what-is-cancer/cells/what-cancer-is>

Cancer cells can either be localised in one area of the body or they can spread and damage other parts of the body via the blood and lymph systems.<sup>2</sup> If the latter occurs, the cancer can start to grow into new tumours. These tumours are called secondary cancers or metastases.

Cancer differs from most other diseases in that it can develop at any stage in life and in any organ in the human body.<sup>3</sup> There are over 200 types of cancer;<sup>4</sup> most are named according to the organ or type of cell in which the cancer originates.

A diagnosis of cancer and its subsequent treatment can have a devastating impact on the quality of a person's life, as well as on the lives of families and other carers. However, almost half of all cancers are preventable. Indeed, many factors can contribute to the risk of an individual developing cancer. These include, for example, the environment (e.g. exposure to toxins, chemicals or sunlight), lifestyle (e.g. smoking and obesity), genetic history, and other factors such as getting older. Whilst cancer can develop at any stage in life, two thirds of those who suffer from cancer are over 65 years of age.<sup>5</sup>

## 2.1 Stages of cancer and survival

Patient pathways for cancer diagnosis, treatment and management are complex and require the involvement of multi-disciplinary teams. The first point of contact for someone who feels unwell or suspects cancer is likely to be their GP. GPs also have a role to play in screening, diagnosis and the long term management of cancer. Where appropriate, GPs will refer cancer patients to the acute hospital system and, if required, on to palliative care, or a number of community-based services.

In general, the progression of cancer is usually determined through a staging process, using a scale from 1 to 4.<sup>6</sup> The early and latter stages are described below.

- 'Stage 1' typically describes a small tumour which has not spread and where no cancer has been detected in the lymph nodes.<sup>7</sup> If the cancer is in one place, then a local treatment in one area of the body - such as surgery or radiotherapy may be used for treatment.
- 'Stage 4' refers to cancer that has spread to major organs in the body (advanced cancer). If a cancer has spread, then a systemic treatment will be required. This involves treating the entire body. Examples include chemotherapy, hormone therapy and other drug treatments which circulate

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<sup>2</sup> National Cancer Institute 'Defining cancer' <http://www.cancer.gov/cancertopics/cancerlibrary/what-is-cancer>

<sup>3</sup> Department of Health and Children 'What is cancer' A Strategy for Cancer Control in Ireland (2006), p 11.

<sup>4</sup> Irish Cancer Society website <http://www.cancer.ie/cancer-information/about>

<sup>5</sup> Cancer Research UK. 'Incidence, survival and mortality' <http://www.cancerresearchuk.org/cancer-help/about-cancer/what-is-cancer/grow/the-stages-of-a-cancer>

<sup>6</sup> The stage of a tumour is based on four things: the size of the tumour; the type of cells in the tumour; whether it has spread to the lymph nodes; and whether it has spread to any other parts of the body.

<sup>7</sup> Cancer Research UK. 'The stages of cancer' <http://www.cancerresearchuk.org/cancer-help/about-cancer/what-is-cancer/grow/the-stages-of-a-cancer>

through the bloodstream. A number of other techniques and complementary therapies are also used to treat various forms of cancer.<sup>8</sup>

In terms of survival, there have been sustained year-on-year improvements in overall cancer survival and mortality.<sup>9</sup> Advances in detection, drug therapies and treatment regimens have contributed to this success.

Although high cure rates can be achieved for some types of cancers, for others, cure rates are low and improved methods of detection and treatment are needed. 'Partial remission' is a term used to describe cases where a cancer may have shrunk or has not grown any bigger. 'Complete remission' is a phrase used when medical tests can no longer detect cancer.

### 3. Cancer Rates

This section of the paper provides an overview of cancer rates in Northern Ireland and the Republic of Ireland.

The incidence of cancer is common. It is a leading cause of death on the island of Ireland.<sup>10</sup> Worryingly, more than one in three people (30% of the population) will develop cancer at some point in their lives.<sup>11</sup> Increased cancer death rates are also linked to deprivation and socioeconomic status.<sup>12,13</sup>

#### 3.1 Northern Ireland

- Northern Ireland has a population of around 1.8 million people.

Cancer data is currently recorded by the *Northern Ireland Cancer Registry* which is based at Queen's University in Belfast. Some key data about the level of cancer in Northern Ireland is shown below:

- In 2012, the main cause of death in Northern Ireland was attributed to cancer (4,134 deaths).<sup>14</sup>
- In 2010, there were 69,377 people living with a past diagnosis of cancer within the last 18 years.<sup>15</sup>
- There are approximately 11,000 new cases of cancer diagnosed in Northern Ireland each year.<sup>16</sup> Prevalence is increasing by 3.2% per annum.
- Non-melanoma skin cancer is the most common form of cancer, but is rarely fatal. Prostate cancer is the most prevalent form of cancer in men and breast cancer is the most prevalent form of cancer in women.

<sup>8</sup> NHS Choices website. 'How is cancer treated?'

<http://www.nhs.uk/chq/Pages/3166.aspx?CategoryID=96&SubCategoryID=226>

<sup>9</sup> Department of Health and Children 'What is cancer' A Strategy for Cancer Control in Ireland (2006), p 11.

<sup>10</sup> National Cancer Registry Ireland 'Cancer facts' <http://www.ncri.ie/fags/cancer-information/what-cancer-cluster>

<sup>11</sup> Irish Cancer Society 'Cancer Statistics' <http://www.cancer.ie/about-us/media-centre/cancer-statistics>

<sup>12</sup> The Northern Ireland Cancer Registry (2010). 'Cancer Incidence and Survival in Northern Ireland.'

<sup>13</sup> McDaid, D. et al (2009) European Observatory 'Health Systems in Transition: Ireland', p14.

<sup>14</sup> NISRA 'Deaths in Northern Ireland' 2012, p1.

<sup>15</sup> Donnelly, D (2010) 'Living with and beyond cancer: A report on cancer prevalence in Northern Ireland' 2010, p1.

<sup>16</sup> Northern Ireland Cancer Registry website. 'Cancer causes and prevention'.

### 3.2 Republic of Ireland

- The Republic of Ireland has a population of 4.6 million people.

The Republic of Ireland has a *National Cancer Registry* which collects data on cancer incidence, treatment and survival. Key statistics include:

- Cancer accounts for over one-quarter of the annual death toll, and is the second most common cause of death in the Republic of Ireland (after circulatory diseases).
- Around 30,000 new cases of cancer are diagnosed each year. This is expected to rise to over 40,000 new cases per year by 2020.
- 29,775 people were diagnosed with cancer in 2009: 15,364 men and 14,441 women.
- The five most common cancers in the Republic of Ireland are: 1) Non melanoma skin cancer; 2) prostate cancer; 3) breast cancer; 4) bowel cancer; and, 5) lung cancer.
- 42% of men and 50% of women diagnosed with cancer currently survive for five years and longer.<sup>17</sup>

According to the Department of Health and Children in the Republic of Ireland, tackling cancer means providing specialist services of a consistently high quality.<sup>18</sup> As the rate of cancer is projected to increase and its progression can be chronic and unpredictable, more demands will be placed on services in terms of long term treatment and care.<sup>19</sup> Furthermore, increased survival rates alongside the increasing aging population, also present challenges in terms of developing services which have the capacity to cope with the level of patient need.

## 4. Cancer services (NI and ROI)

### 4.1 Differences between models of care

This section of the paper outlines cancer service provision in Northern Ireland and the Republic of Ireland. Both healthcare systems are undergoing a process of reform which aims to make more effective use of resources.<sup>20</sup> Importantly, policy proposals for reform have placed greater emphasis on integrated care and strengthening primary care services. Another key area focuses on treating people in the community and closer to their own homes.<sup>21</sup>

<sup>17</sup> Statistics available from the Irish Cancer Society <http://www.cancer.ie/about-us/media-centre/cancer-statistics>

<sup>18</sup> Department of Health and Children 'What is cancer' A Strategy for Cancer Control in Ireland (2006), p 11.

<sup>19</sup> Department of Health and Children (ROI) and Department of Health, Social Services and Public Safety: North South Feasibility Study, p39.

<sup>20</sup> See DHSSPS Northern Ireland Transforming Your Care (2012), and Department of Health (Ireland) Future Health A Strategic Framework for Reform of the Health Service 2012 – 2015 (published 2012)

<sup>21</sup> See *Transforming Your Care* (Northern Ireland) and *Future Health* (Ireland)

However, readers should also be aware that both jurisdictions, as well as having different population sizes (with the Republic having more than double the population of Northern Ireland), operate different healthcare systems in terms of governance, structure and legislation. These factors can have implications in terms of services operating on a cross-border basis.

An example which highlights a key difference between the two healthcare systems is how care is paid for. Whilst both systems are largely tax funded, in Northern Ireland access to primary care (and healthcare in general) is free to all 'ordinary residents' at the point of delivery.<sup>22</sup> However, in the Republic of Ireland access to healthcare services is currently funded through a complex public and private mix; the majority of the population are considered 'private patients' who pay independently or are required to take out insurance to pay fees in order to access a GP, hospital care, and prescription drugs.<sup>23,24</sup> The remaining 30% of the population are entitled to free healthcare if they are in receipt of a *medical card* or a *GP visit card*.<sup>25</sup>

## 4.2 Northern Ireland – development of cancer services

Cancer services in Northern Ireland have changed radically in the last 15 years.

- In 1996, the first major review of cancer services in Northern Ireland was undertaken. This was known as the *Campbell Report*.<sup>26</sup> Given the size of the population and the cost of specialist equipment, the report recommended a new model for cancer services, based on a regional cancer centre and supporting cancer units. This model proposed that the centralisation of services would help patients receive more joined-up cancer care and expertise in the management of their illness. Since the Campbell Report, four cancer units and a regional cancer centre have been established (discussed below).

Around 2007, the health and social care system went through an extensive restructuring exercise under the Review of Public Administration (RPA).<sup>27</sup> Following this, the responsibility to plan, secure and commission healthcare services in Northern Ireland (including cancer services) was given to the Health and Social Care (HSC) Board<sup>28</sup> which was created under the RPA. The HSC Board commissions cancer services from the five local Health and Social Care Trusts and from charitable organisations.

<sup>22</sup> DHSSPS Circular HSS (PCD) 10/2000.

<sup>23</sup> It has been argued that charging patients can deter them from accessing healthcare systems, and can lead to inequalities; adding to delays in preventing or treating serious illnesses, such as cancer. Interestingly too is that, data shows that patients in Northern Ireland (with free access to healthcare) visit their GP more than twice as often as those in the Republic of Ireland.

<sup>24</sup> Please note, under the Future Health publication, the healthcare system in Ireland is due to reform access to healthcare making it more universally available.

<sup>25</sup> Health Service Executive 'All about Medical Cards' <http://www.hse.ie/eng/services/list/1/schemes/mc/about/>

<sup>26</sup> DHSS (1996) 'Cancer Services – Investing for the Future'

<sup>27</sup> DHSSPS website, RPA <http://www.dhsspsni.gov.uk/rpa-home>

<sup>28</sup> Health and Social Care Board Website <http://www.hscboard.hscni.net/>

Each year, the HSC Board – (in association with the Public Health Agency), produces a “Commissioning Plan” which is based on the Minister for Health, Social Services and Public Safety’s (HSSPS) Commissioning Plan Direction.<sup>29</sup> Within the Plan, commissioning teams have been created to reflect a number of ‘service areas’. One of those areas is for ‘cancer services’. The current Plan (2013/14) includes a number of key deliverables in the area of cancer services to be achieved for the year ahead.<sup>30</sup>

#### 4.3 Cancer units and cancer centre

Figure 1 shows the location of the **cancer units and the Cancer Centre in Northern Ireland**. The cancer units are located in Altnagelvin Hospital (Western Trust), Antrim Hospital (Northern Trust), Craigavon Hospital (Southern Trust), Ulster Hospital (South Eastern Trust) and the Belfast City Hospital & Royal Victoria Hospitals (Belfast Trust).<sup>31</sup> These units provide care for people with more common cancers, such as lung, breast and colorectal cancer.<sup>32</sup> They also provide chemotherapy services, which can enable people to be treated closer to their own homes. Nevertheless, services for less common cancers are shared between the units and the Regional Cancer Centre in Belfast.

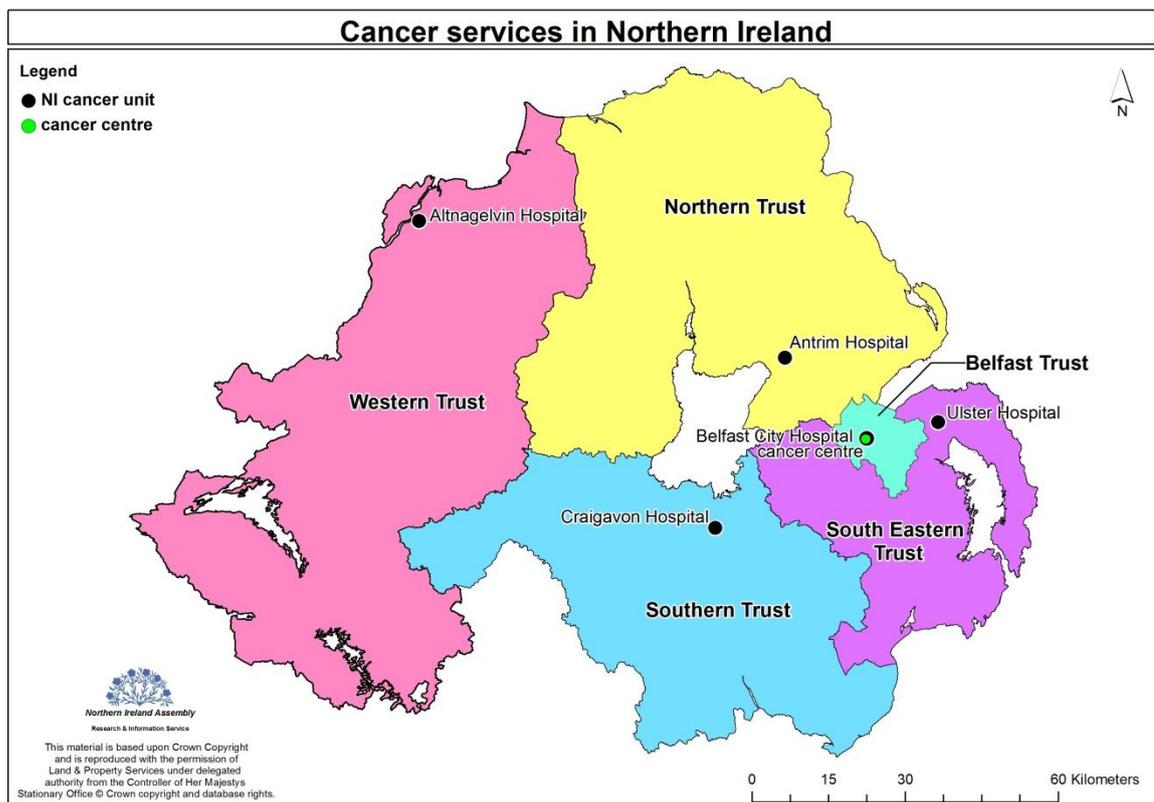


Figure 1 Cancer units and the Cancer Centre, Northern Ireland

<sup>29</sup> See HSCB and PHA 2013/14 Commissioning Plan

<http://www.hscboard.hscni.net/board/meetings/20130314%20March%202013/Item%2009%20-%2002%20-%20Commissioning%20Plan%20Board%202013-14%20PDF%20%2064MB.pdf>

<sup>30</sup> See HSCB and PHA 2013/14 Commissioning Plan, pp85-92.

<sup>31</sup> NICaN Website: 'Role of the cancer units'

<http://www.cancerni.net/cancerinni/overviewofcancerservicesinnorthernireland/roleofthecancerunits>

<sup>32</sup> Ibid

Northern Ireland's **Regional Cancer Centre** opened in 2006.<sup>33</sup> It is located at the City Hospital site in Belfast (although some cancer services are also provided at the Royal Victoria, Musgrave Park and the Mater Hospitals in Belfast). The Cancer Centre facilitates radiotherapy, chemotherapy and a range of outpatients, day case and inpatient services. It also specialises in the treatment of less common cancers and those with cancer who are undergoing complex or radical treatments such as radiotherapy and specialist surgeries.<sup>34</sup>

In terms of accessibility to the Cancer Centre, over half of the population of Northern Ireland lives within the greater Belfast area. However, there are still a number of patients living in more rural areas - particularly in the west of Northern Ireland. For them, travelling to their local cancer unit or to the Cancer Centre when sick can be particularly stressful and arduous.

Interestingly, whilst the Belfast Trust operates the specialised cancer centre, it does not have the overall highest patient population. Data from Table 1 shows that in 2010, the Northern Trust had the greatest patient population (458,746), and the Western Trust the least (299,431). Table 1 also illustrates how the patient population is growing. These trends will inevitably place increasing demands on the various cancer services in Northern Ireland.

Trust	2008	2009	2010	% change 2008-2010
Belfast	334,528	335,150	335,774	0.4%
Northern	453,824	457,101	458,746	1.1%
S Eastern	341,085	344,434	346,794	1.7%
Southern	348,657	353,908	358,647	2.9%
Western	296,909	298,303	299,431	0.8%
<b>NI</b>	<b>1,775,003</b>	<b>1,788,896</b>	<b>1,799,392</b>	<b>1.4%</b>

Table 1. Total Northern Ireland patient population by Trust area (2008-2010)<sup>35</sup>

In addition to the cancer units and the Cancer Centre, the health service in Northern Ireland works closely with a number of charities to provide cancer services in the community. Examples include Macmillan, Marie Curie Hospice, Action Cancer, and the Cancer Focus NI. These organisations provide a range of cancer services from screening, prevention, various types of support (including financial help for cancer patients) and palliative care. There are also a number of other specific cancer charities and voluntary groups providing help and support to cancer patients and their families, for example, 'Clic Sargent' - a cancer charity for children, and 'Pretty n' Pink' - a charity for breast cancer.

<sup>33</sup> Belfast Trust. 'Cancer Services' <http://www.belfasttrust.hscni.net/services/CancerServices.htm>

<sup>34</sup> NICaN website 'Role of the cancer centre' <http://www.cancerni.net/cancerinni/overviewofcancerservicesinnorthernireland/roleofthecancercentre>

<sup>35</sup> DHSSPS 'Contextual information for using hospital statistics', p3. Available online at: [http://www.dhsspsni.gov.uk/population\\_in\\_northern\\_ireland.pdf](http://www.dhsspsni.gov.uk/population_in_northern_ireland.pdf)

In order to complement the various stakeholders who provide support to cancer patients, the Northern Ireland Cancer Network (NICaN) was established in 2004.<sup>36</sup> This regionally managed clinical network aims to support health professionals, patients and charities so they can share good practice and work in a more co-ordinated way.<sup>37</sup> The Network also provides a directory of cancer services.

#### 4.4 Departmental policies and strategies in Northern Ireland

Evidence suggests that around half of all cancers could be prevented if people made changes to their lifestyle.<sup>38</sup> Therefore, prevention remains a central focus of cancer policy.<sup>39</sup> Departmental policies in both jurisdictions have emphasized individual responsibility in preventing cancer - in other words, the risk of developing cancer can be minimized when people adopt healthy lifestyle behaviors; such as not smoking, reducing alcohol intake, eating a healthy balanced diet, keeping active, and avoiding the sun.<sup>40</sup> Policies such as Northern Ireland's "*Fit and Well (2012-2022)*" focus on these issues.<sup>41</sup>

However, the government also admits that more needs to be done to increase awareness about the risks, signs and symptoms of cancer, and that a multi-agency approach should be adopted.<sup>42,43</sup> Whilst it is beyond the scope of this current paper to list all the relevant departmental policies, the main cancer policies for Northern Ireland include:

- DHSSPS *Regional Cancer Framework (Cancer Control Programme, 2007)*.<sup>44</sup> This framework was designed to reduce the burden of cancer. It sets out a number of recommendations and actions for the further strengthening of cancer services and the setting of standards for the delivery of those services.
- DHSSPS *Service Framework for Cancer Prevention, Treatment & Care (2011)*.<sup>45</sup> This 3 year service framework focuses on people who already have cancer. It sets standards about cancer care across the patient journey from prevention, diagnosis, treatment; rehabilitation, and palliative and end of life care.

Other DHSSPS policies which tie in with those listed above (although not an exclusive list), include the *Skin Cancer Prevention Strategy (2010-2020)*<sup>46</sup>, and the *'Living*

<sup>36</sup> NICaN <http://www.cancerni.net/>

<sup>37</sup> NICaN website <http://www.cancerni.net/cancerinni/yourcancernetwork1>

<sup>38</sup> DHSSPS 'Service Framework for Cancer Prevention, Treatment & Care', p 57

<sup>39</sup> Department of Health and Children 'What is cancer - A Strategy for Cancer Control in Ireland' (2006), p 11.

<sup>40</sup> NHS Choices website. 'Reduce your cancer risk'

<http://www.nhs.uk/Livewell/preventing-cancer/Pages/diet-and-cancer.aspx>

<sup>41</sup> DHSSPS 'Fit and Well 2012-22' <http://www.dhsspsni.gov.uk/fit-and-well-consultation-document.pdf>

<sup>42</sup> HSCB and PHA Commissioning Plan 2013/14, p83.

<sup>43</sup> DHSSPS (2007) Regional Cancer Framework, p23.

<sup>44</sup> DHSSPS (2007) Regional Cancer Framework

[http://www.dhsspsni.gov.uk/eeu\\_cancer\\_control\\_programme\\_eqia.pdf](http://www.dhsspsni.gov.uk/eeu_cancer_control_programme_eqia.pdf)

<sup>45</sup> DHSSPS Service Framework for Cancer Prevention, Treatment & Care. Available online at [http://www.dhsspsni.gov.uk/service\\_framework\\_for\\_cancer\\_prevention\\_treatment\\_and\\_care\\_-\\_full\\_document.pdf](http://www.dhsspsni.gov.uk/service_framework_for_cancer_prevention_treatment_and_care_-_full_document.pdf)

<sup>46</sup> DHSSPS <http://www.dhsspsni.gov.uk/skin-cancer-prevention-strategy-2010.pdf>

*Matters: Dying Matters' Palliative and End of Life Care Strategy for Northern Ireland* (2010).<sup>47</sup>

#### 4.5 Other initiatives

In addition to the various policies and strategies:

- the Public Health Agency (Northern Ireland) has launched several campaigns to increase awareness and promote healthier lifestyle choices, such as the “reduce smoking” campaign (September 2013);<sup>48</sup>
- Northern Ireland currently has 3 screening programmes for bowel, breast and cervical cancer;<sup>49</sup>
- The DHSSPS set a number of targets in relation to cancer. One target aims to increase the uptake of bowel cancer screening. Another target is to ensure that the majority of patients urgently referred with a suspected cancer receive their first definitive treatment within 62 days.<sup>50</sup> Unfortunately, recent correspondence with the DHSSPS has confirmed that both of these targets for the 2012-13 time frame have not been met.<sup>51</sup>

#### 4.6 Costs to patients

##### Northern Ireland

Cancer results in costs to patients and can place families in financial difficulty. Treatment often means that patients have to take sick leave, reduce hours, or give up their jobs altogether – thus adding to costs to the economy.<sup>52</sup> There can be other financial costs such as those associated with child care, when treatment is necessary.

Whilst cancer services are largely provided free of charge to ordinary residents in Northern Ireland, a recent report by *Macmillan Cancer* (2013) showed that three out of four people in Northern Ireland are financially affected as a result of a cancer diagnosis. This is due to a reduced income for time off work and increased expenses.<sup>53</sup> The report suggests cancer patients are around £290 worse off each month.<sup>54</sup> Increased heating bills to keep warm after treatment, and travel costs associated with medical appointments (especially for patients who live further away) are just two examples of the types of costs being incurred.<sup>55</sup> Because of the financial burden a diagnosis of cancer can bring, there are a number of organisations working to

<sup>47</sup> DHSSPS [http://www.dhsspsni.gov.uk/8555\\_palliative\\_final.pdf](http://www.dhsspsni.gov.uk/8555_palliative_final.pdf)

<sup>48</sup> Public Health Agency website. See for example: <http://www.publichealth.hscni.net/news/major-new-smoking-campaign-focuses-family-impact>

<sup>49</sup> Public Health Agency website. ‘Cancer Screening Programmes’ <http://www.cancerscreening.hscni.net/>

<sup>50</sup> DHSSPS The Health and Social Care (Commissioning Plan) Direction (Northern Ireland) 2012, p4.

<sup>51</sup> Personal correspondence between author and DHSSPS response dated 5/9/13.

<sup>52</sup> BBC News (NI) April 2013. ‘NI cancer patients struggle to pay bills, charity research shows’. <http://www.bbc.co.uk/news/uknorthern-ireland-22208532>

<sup>53</sup> Macmillan Cancer (2013) ‘Cancer’s hidden price tag – revealing the cost behind the illness’.

<sup>54</sup> Ibid, p4.

<sup>55</sup> At present, under a regional document for Northern Ireland, many patients suffering from cancer and other serious long term conditions are entitled to free parking at hospitals. See DHSSPS guidance: <http://www.dhsspsni.gov.uk/car-parking-provision.pdf>

ensure that people affected by cancer receive appropriate information about benefits available to them.<sup>56</sup>

There can also be other costs associated with treatment. Specialist cancer drugs are expensive and clinical trials take a long time to complete. At present, the criteria for accessing new cancer drugs is under review in Northern Ireland.<sup>57</sup> Healthcare Trusts work on the principle that if the National Institute of Clinical Excellence (NICE) – which is a UK body, recommends that a drug should not be used within the NHS, it is unlikely to be funded in Northern Ireland. According to a report by the Rarer Cancers Foundation, there are around 20 such cancer drugs currently unavailable in Northern Ireland.<sup>58</sup> However, these drugs may be available to patients living in England who have access to a special £200 million Cancer Drugs Fund<sup>59</sup>, and it has been suggested that a cancer ‘drugs divide’ across the UK is occurring.<sup>60</sup> Patients from Northern Ireland who require treatment or care that falls outside of the range of services normally commissioned by the Board can contact their clinician who can apply for an *Individual Funding Request* or an *Extra Contractual Referral*.<sup>61,62</sup> However this does not guarantee a treatment or drug will be granted. In addition, a recent report by the Rarer Cancers Foundation (2012) was highly critical of the local healthcare system for delays and variations in arrangements for these funding referral processes.<sup>63</sup>

Individuals may also decide to pay for cancer drugs privately if they are not available through other means. Nevertheless, this investment in drugs can cost patients thousands of pounds<sup>64</sup> and sometimes patients simply cannot afford such treatments.

In terms of recent pharmaceutical advances, Almac, a Northern Ireland company, in association with Queen’s University Belfast, has developed a promising new cancer drug which is undergoing further clinical testing which may be available in the future to patients in Northern Ireland and further afield.<sup>65</sup>

<sup>56</sup> NICaN ‘Financial Help’ <http://www.cancerni.net/node/1458>

<sup>57</sup> Macmillan Website: ‘Cancer treatment’.  
<http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Gettingtreatment/Accessstotreatment/Whatyouroctorcandoforyou/NorthernIreland.aspx>

<sup>58</sup> Rarer Cancers Foundation (2012) ‘Funding cancer drugs in Northern Ireland’ Available online at:  
[http://www.rarercancers.org/index.php?option=com\\_content&view=article&id=261:rcf-calls-for-solution-to-address-restrictions-on-access-to-cancer-drugs-in-northern-ireland&catid=44:northern-ireland-news&Itemid=5](http://www.rarercancers.org/index.php?option=com_content&view=article&id=261:rcf-calls-for-solution-to-address-restrictions-on-access-to-cancer-drugs-in-northern-ireland&catid=44:northern-ireland-news&Itemid=5)

<sup>59</sup> NHS England (April 2013) New Single drug fund list to bring fairer system for cancer patients  
<http://www.england.nhs.uk/2013/04/04/cdf/>

<sup>60</sup> Pharmanews (April 2011) UK’s cross-border divide in cancer drug access is growing

<sup>61</sup> NI Assembly Question AQW 21549/11-15 Mr Conall McDevitt to ask HSSPS Minister what assurances he can give that patients in Ni are afforded the same opportunity for specialist cancer treatment as those in Britain.

<sup>62</sup> HSC Board HSC Arrangements for requests for care.  
[http://www.hscbusiness.hscni.net/pdf/Protocol\\_ECR\\_and\\_IFR\\_arrangements.pdf](http://www.hscbusiness.hscni.net/pdf/Protocol_ECR_and_IFR_arrangements.pdf)

<sup>63</sup> See: Rarer Cancers Foundation (2012) ‘Funding cancer drugs in Northern Ireland’.

<sup>64</sup> Macmillan Website: ‘Other things you can do if treatment isn’t available’.  
<http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Gettingtreatment/Accessstotreatment/Otherthingsyoucando.aspx>

<sup>65</sup> BBC Website 5 Sept 2013. ‘Milestone reached in Belfast cancer 5 research’ <http://www.bbc.co.uk/news/uk-northern-ireland-23967850>

#### 4.7 Republic of Ireland – cancer strategies and services

Historically, cancer services in the Republic of Ireland were fragmented across many hospital sites.

- In 1996, the *National Cancer Strategy* made a series of recommendations about increasing capacity and funding in order to ensure the availability of cancer services; particularly hospital services. After the publication of the first strategy, the National Cancer Forum was established. Its aim was to provide independent policy advice on cancer to the Minister.

In 2005, a major restructuring exercise of the Republic of Ireland’s healthcare system took place. The overall responsibility for the healthcare system falls to the Department for Health and Children. The Health Service Executive (HSE), which replaced the former health boards, is charged with providing health and social care services – including cancer services.<sup>66</sup>

- Following an evaluation of the first cancer strategy, the Department of Health and Children developed a second cancer strategy. Entitled ‘*A Strategy for Cancer Control in Ireland*’ (2006),<sup>67</sup> the second strategy concluded that there was “*inequity in the availability of, access to, and performance of, cancer services throughout the country*”.<sup>68</sup> A number of recommendations were made to improve cancer services - some of which are highlighted overleaf.<sup>69</sup>

- Cancer care should be provided through a national system of four Managed Cancer Control Networks, each serving a population of around 1 million;
- Each Network should have comprehensive specialist palliative care, psycho-oncology and psychosocial support services;
- 8 Cancer Centres should be created - serving a minimum population of 500,000.
- Patients should have their diagnosis established and their treatment planned by site-specific multidisciplinary teams;
- The creation of service level agreements between the Health Service Executive and the private sector for specific cancer services will enable a cooperative relationship between the public and private sector;
- A partnership framework should be developed between the Health Service Executive and the voluntary sector.

Many of the recommendations in the strategy were similar to those identified for Northern Ireland – such as the centralisation of services, the emphasis on clinical teams, and partnerships with other sectors. A number of developments then followed:

<sup>66</sup> McDaid, D. et al (2009) European Observatory ‘Health Systems in Transition: Ireland’.

<sup>67</sup> Department of Health and Children (2006): ‘A Strategy for Cancer Control in Ireland’, p47.

<sup>68</sup> Ibid, p27.

<sup>69</sup> Department of Health and Children ‘What is cancer - A Strategy for Cancer Control in Ireland (2006)’, p 45.

- In 2007 the HSE established a National Cancer Control Programme to manage and deliver a national cancer programme for the Irish population.<sup>70</sup>
- Today the Republic of Ireland has 8 specialist cancer centres. In addition there is a satellite (outreach) cancer centre in Letterkenny. Four of the cancer centres are located in the Dublin area. The four HSE regions have two cancer centres in a 'Managed Cancer Control Network' as was recommended in the Cancer Control Strategy. These are as follows:

<b>HSE Dublin North East</b> Beaumont Hospital Mater University Hospital	<b>HSE Dublin Mid-Leinster</b> St James's Hospital St Vincent's University Hospital
<b>HSE South</b> Cork University Hospital Waterford Regional Hospital	<b>HSE West</b> Mid Western Regional Hospital Galway University Hospital

- Each cancer centre is designed to have broad self-sufficiency in respect of the most common cancers.<sup>71</sup>
- Initial diagnosis and surgery largely takes place within these cancer centres. Chemotherapy and follow-up care will be delivered more locally, according to the care plans established at the cancer centres.<sup>72</sup> There are also around 20 hospitals in the Republic that can deliver some form of chemotherapy. Community nurses are trained, for example to care for infections, and to disconnect pumps, so that patients do not have to make repeated journeys back to their treatment centres.
- A range of voluntary and charitable organisations also support cancer patients, their carers and families in the Republic of Ireland. These include the Irish Cancer Society,<sup>73</sup> the Marie Keating Foundation<sup>74</sup> and the ARC Cancer Support Centre<sup>75</sup> to name but a few.

The geographical location of each of the specialist cancer centres in the Republic of Ireland is shown on the map in Figure 2 overleaf. As can be seen from the map, there are several areas - especially along the west of Ireland where patients will have longer journeys to the appropriate cancer centre. Those in Donegal can also avail of services

<sup>70</sup> Health Service Executive 'National Cancer Control Programme'

<http://www.hse.ie/eng/services/list/5/nccp/about/>

<sup>71</sup> Health Service Executive. 'About the National Cancer Control Programme'

<http://www.hse.ie/eng/services/list/5/nccp/about/>

<sup>72</sup> Citizens Information website. 'Cancer Services'

[http://www.citizensinformation.ie/en/health/cancer\\_services/cancer\\_services.html](http://www.citizensinformation.ie/en/health/cancer_services/cancer_services.html)

<sup>73</sup> Irish Cancer Society <http://www.cancer.ie/about-us>

<sup>74</sup> Marie Keating Foundation <http://www.mariekeating.ie/>

<sup>75</sup> ARC Cancer support centre <http://www.arccancersupport.ie/>

in Altnagelvin Hospital or Belfast City Hospital in Northern Ireland which is discussed further in section 6 of this paper.<sup>76</sup>



Figure 2. Cancer centers in the Republic of Ireland.<sup>77</sup>

#### 4.8 Departmental policies and strategies in the Republic of Ireland

- The Department of Health and Children has advised that there are no further strategies on cancer in addition to the main cancer strategy 2006.<sup>78</sup> However,

<sup>76</sup> Personal correspondence with Dr Susan O'Reilly, Director of the National Cancer Control Programme, Ireland on 24.9.13.

<sup>77</sup> Health Service Executive, 'Regional Cancer Centres'

[http://www.hse.ie/eng/services/list/5/nccp/about/Map\\_of\\_Regional\\_Cancer\\_Centres.pdf](http://www.hse.ie/eng/services/list/5/nccp/about/Map_of_Regional_Cancer_Centres.pdf)

<sup>78</sup> Personal correspondence between the author and Fiona Conroy (Department of Health & Children). Response dated 20.9.13.

the Department has in place a number of strategies to increase general healthy lifestyle choices such as smoke free environments, reducing alcohol consumption and promoting physical activity – see the 'Healthy Ireland' Framework (2013-2025).<sup>79</sup> There are also palliative care policies for children and adults, and hospice services provided in collaboration by the Irish Hospice Foundation, the Department of Health and the HSE;<sup>80</sup>

- The National Cancer Control Programme has established national expert Tumour Groups comprising expert leads in relevant clinical disciplines to develop and promulgate national clinical practice guidelines for cancer services.<sup>81</sup>
- A National Cancer Screening Service was established by the Minister for Health and Children in January 2007.<sup>82</sup> Similar to Northern Ireland, the Republic of Ireland currently offers three national cancer screening programmes; a breast check programme for women aged 50-64; a cervical check programme for women aged 25-60 and more recently, a bowel screening programme for anyone aged 60-69, although it will eventually extend to the 55-74 age group.<sup>83</sup>

## 5. Government Funding

The costs to the health service for the diagnosis and treatment of cancer is substantial.<sup>84</sup> In Northern Ireland, the DHSSPS has advised that cancer services are provided through multiple funding streams rather than one specific cancer services budget and that costs are difficult to disentangle.<sup>85</sup> Substantial palliative care and other community and personal social services are provided in support of people with cancer, but this information is also not available centrally.<sup>86</sup>

The same issue is faced in the Republic of Ireland. The National Cancer Control Programme (NCCP) has stated:

*“It is not possible to determine accurately the cancer budget in the Republic of Ireland as the majority of funding is embedded within the acute hospital general budget and is part of their overall allocation. While dedicated additional development funding has been allocated to cancer in recent years, this is only a fraction of the overall budget...”*

*The NCCP has begun to collect the annual costs of a selected number of high cost cancer drugs from public hospitals (no private hospital costs are included) but these do not include costs of supportive therapy. Indicative costs are available in relation to expenditure on oral medication dispensed under the*

<sup>79</sup> Health Ireland Framework <http://www.dohc.ie/publications/pdf/HealthyIrelandBrochureWA2.pdf?direct=1>

<sup>80</sup> Personal correspondence between the author and Fiona Conroy (Department of Health & Children). Response dated 20.9.13.

<sup>81</sup> Ibid

<sup>82</sup> 'National Cancer Screening Service' (Ireland) <http://www.cancerscreening.ie/>

<sup>83</sup> Ibid.

<sup>84</sup> Sharp, L and Timmons A. (2010) 'The Financial impact of a cancer diagnosis', p1.

<sup>85</sup> Personal correspondence between author and DHSSPS response dated 21.8.13

<sup>86</sup> Personal correspondence between author and DHSSPS response dated 21.8.13

*various community schemes (high tech scheme, medical cards and the drug payment scheme). The NCCP has its own internal budget which funds some priority clinical initiatives and a budget to run the national cancer screening (& diabetic retinopathy) services but this is minimal in the context of the national budget.”<sup>87</sup>*

## 5.1 Costs of cancer care per capita

As cancer treatment is wide and varied, the DHSSPS has advised that it does not currently have details on per capita spend in terms of cancer services.

Like Northern Ireland, the cancer services budget in the Republic of Ireland is difficult to dissect and per capita costs will not be available for several years.<sup>88</sup> The difficulties are summarised by the National Cancer Control Programme which states:

*“The case mix system in use is not accurate to be able to determine the full costs of cancer care in [the Republic of] Ireland - in addition just under 50% of the population has private health insurance and patients can be treated in a public or private setting. The HSE/NCCP have no details on cancer expenditure in the private system.”<sup>89</sup>*

In turn, the following questions posed:

- How much per capita do cancer services cost island-wide (North and South) and;
- How do these costs per capita compare with similar provisions which are offered in the North and in the South?

cannot be determined for either jurisdiction.

However, to give some indication of the level of spend in Northern Ireland, the DHSSPS has advised that some data is available on the cost of cancer care for ‘inpatient episodes’ and ‘day-case’ hospital attendances for patients with a primary diagnosis of cancer. Table 2, provided by the DHSSPS, gives a summary of all identifiable costs relating to cancer treatment as a proportion of total expenditure in a hospital setting for 2011/12. It should be borne in mind that these costs represent only a proportion of the cost of activity attributed to cancer patients. Given this caveat, ‘inpatient’ and ‘day case’ cancer medicines cost approximately £26 million in 2011/12.<sup>90</sup> Overall, cancer costs for ‘inpatient’ and ‘day cases’ in Northern Ireland in 2011/12 totalled £141 million.<sup>91</sup>

<sup>87</sup> Personal Correspondence with Fidelma MacHale, Cancer Control Programme, response dated 1.10.13.

<sup>88</sup> Personal correspondence with Dr Susan O’Reilly: Director of the National Cancer Control Programme, Ireland on 24.9.13.

<sup>89</sup> Personal Correspondence with Fidelma MacHale, Cancer Control Programme, response dated 1.10.13.

<sup>90</sup> Personal correspondence between author and DHSSPS response dated 21.8.13

<sup>91</sup> Personal correspondence between author and DHSSPS response dated 21.8.13

Point Of Treatment	Cost 2011/12	Total Hospital Expenditure 2011/12
Inpatients	71,900,135	
Day-case attendances	15,003,933	
Total day-case and inpatient expenditure excluding chemotherapy and radiotherapy drugs	86,904,068	
Chemotherapy and radiotherapy drugs costs for inpatients and day-cases	25,967,472	
Chemotherapy delivery day-cases (based on 2008-09 costs)	8,954,292	
<b>Inpatient and day-case total</b>	<b>121,825,832</b>	<b>1,254,511,837</b>
<b>Outpatient total</b>	<b>19,837,683</b>	<b>423,362,900</b>
Day care	0	9,693,621
<b>TOTAL</b>	<b>141,663,515</b>	<b>1,687,568,358</b>

Table 2 Inpatient and day case hospital costs for cancer 2011/12 (Northern Ireland)

## 6. Cross border collaboration in relation to cancer care

The final section of this paper considers current cross border cancer service arrangements.

The DHSSPS has confirmed that an 'all island' cancer facility does not exist at present<sup>92</sup> and that the numbers of patients travelling across the border for treatment is small.<sup>93</sup> Nevertheless, a number of on-going arrangements are in place which allow for co-operation regarding cancer services. These include:

- In 1999, a historic tripartite *memorandum of understanding* (MOU) was signed by the Department of Health in Ireland, the DHSSPS (NI) and the United States Department of Health and Human Services. This established the *Ireland-Northern Ireland-National Cancer Institute (NCI) Cancer Consortium* – which was a direct outcome of US involvement in the Belfast (Good Friday) Agreement.<sup>94</sup> The mission of the Consortium was to lessen the burden of cancer across Ireland (North and South) through cross-border and transatlantic collaborations in cancer research and education. The Consortium has developed a number of joint programs including prevention, clinical trials, cancer registries and epidemiology, and scholarly exchanges. Since its inception, a number of hospitals have been funded to support high-quality clinical trials. More recently (2012) the consortium has developed five workstreams including:
  - Capacity Building for Clinical Research;
  - Public Health & Wellbeing/Prevention/Health Promotion;

<sup>92</sup> Personal correspondence with the DHSSPS and the author, response dated 22.8.13.

<sup>93</sup> Personal correspondence with Dr Susan O'Reilly: Director of the National Cancer Control Programme, Ireland on 24.9.13.

<sup>94</sup> National Cancer Institute website. 'All-Ireland NCI Cancer Consortium'

- Nursing;
- Palliative and End-of-Life Care; and
- Survivorship

In 2011 the Cancer Consortium MOU was extended for an additional five years.<sup>95</sup>

- In terms of cross-border collaboration, a *service level agreement* for Donegal cancer patients to access radiotherapy services in Belfast City Hospital and Altnagelvin Hospital was agreed in 2006 and still stands. Patients from the Republic of Ireland can also attend Altnagelvin Hospital in Northern Ireland for pathology services for lung cancer diagnosis.<sup>96</sup> In terms of patient numbers, only a small number from the Republic are treated with radiotherapy in Belfast City Hospital (this agreement also covers appointments in Altnagelvin). For example, in 2012 two people were treated at a cost of £15k; in 2011 four people were treated at a cost of £34k, and in 2010, six people were treated at a cost of £72k.<sup>97</sup> Whilst Republic of Ireland patients are offered treatment in Belfast City hospital where appropriate, the National Cancer Control Programme states that most patients choose to attend St. Luke's hospital in Dublin.
  - Payments for patients from the Republic of Ireland who are treated in the North is made either under the terms of a previously agreed service level agreement, or via a cost-per-case basis, previously agreed between the health organisations.<sup>98,99</sup>
- The DHSSPS has confirmed that a small number of patients have attended hospitals in the Republic - such as Beaumont Hospital in Dublin and Sligo General Hospital for radiotherapy or radiosurgery treatment.<sup>100,101</sup>
- A Memorandum of Understanding (MOU) for a specific £70 million radiotherapy unit at Altnagelvin Hospital in Northern Ireland has been agreed and signed in 2012.<sup>102</sup> Funding for the service will be provided by the Departments of Health on both sides of the border. The Irish Government has committed capital funding of one third of the building cost (up to a maximum

<sup>95</sup> National Cancer Institute. 'All island cancer consortium'.

<http://www.cancer.gov/aboutnci/globalhealth/europe/aicc>

<sup>96</sup> Personal correspondence with the DHSSPS and the author, response dated 22.8.13.

<sup>97</sup> Personal Correspondence with Fidelma MacHale, Cancer Control Programme, response dated 1.10.13.

<sup>98</sup> Personal correspondence with the DHSSPS and the author, response dated 22.8.13.

<sup>99</sup> The National Cancer Control Programme has stated that patients are not charged and invoices for these patients are sent to Letterkenny Hospital.

<sup>100</sup> AQW14163/11/-15 Mr Conall McDevitt to ask HSSPS Minister to detail the number of cancer patients who were sent outside NI from radiotherapy or radiosurgery treatment in each of the last five years.

<sup>101</sup> "The Health and Social Care board has approved a number of patients for treatment in the RoI, however it is not possible to confirm if, or how many of, these were for cancer treatments. These patients are funded through extra contractual referral (ECR) to the RoI." [DHSSPS response]

<sup>102</sup> Personal correspondence with the DHSSPS and the author, response dated 22.8.13.

ROI contribution of €19 million), given that approximately one third of the patients will be from Donegal and surrounding areas.<sup>103</sup> The unit will be managed by the Western Health and Social Care Trust. Construction will commence in 2013, with the unit opening in 2016.<sup>104</sup> It will provide more locally accessible services and improve patient travelling times for patients; for example, the site will enable cancer patients from the west of Northern Ireland and Donegal to access radiotherapy services.<sup>105</sup> This will inevitably save Donegal patients the journey to Dublin<sup>106</sup>, and likewise those from areas around Londonderry/Derry from having to travel to Belfast for treatment.

In terms of the factors taken into account when planning services on a cross border basis, the DHSSPS went on to say:

*“A business case is developed for any joint service between the two jurisdictions; [this includes] a full cost benefit analysis (capital and revenue); the strategic context; current service provision and demand; the case for change, objectives and constraints; financial, non-financial and economic analysis; affordability and sustainability; and value for money, as well as quality standards and equality impact assessment. The cost profiles of any type of joint working arrangements depend on the nature of the services being considered for development. A critical factor in gaining approval is being able to demonstrate that the costs are well understood, affordable and provide value for money. In the case of Altnagelvin radiotherapy unit, benefits in terms of sustainability and accessibility should be significant.”<sup>107</sup>*

The National Cancer Control Programme in the Republic of Ireland stated that similar factors need to be taken into account when planning joint services:

*“...Current population need, population projected need, access, current service provision, configuration of services, costs and benefits of shared service provision...”<sup>108</sup>*

Additionally, there will always be advantages and disadvantages in having centralised cancer services. Some of the advantages of having regional cancer units in the current centralised model include for example:

- Patients have access to clinical expertise - multidisciplinary teams and specialist equipment that only deal with cancer can lead to better outcomes;
- Specialist medical knowledge is developed and retained under one roof; teams increase their knowledge;

<sup>103</sup> Personal Correspondence with Fidelma MacHale, Cancer Control Programme, response dated 1.10.13.

<sup>104</sup> North South Ministerial Council. Paper NSMC HEFS 2 (12) JC

<sup>105</sup> Belfast Telegraph, March 2013 survivors delighted as cancer unit plans are approved by Minister.

<sup>106</sup> Forecasted patient numbers outlined in the business case are 385 from the Republic of Ireland in 2017 - representing 25% of the number treated, rising to 424 in 2020 - representing 27% of the number treated.

<sup>107</sup> Personal correspondence with the DHSSPS and the author, response dated 22.8.13.

<sup>108</sup> Personal Correspondence with Fidelma MacHale, Cancer Control Programme, response dated 1.10.13.

- Staff can have better training opportunities; they are more likely to be attracted to major centres of learning and thus more likely to retain their jobs;
- Patients from across the border can access some services eg Altnagelvin etc.

Some of the disadvantages of having centralised services include:

- Access: care may not be available to all people on an equal basis (for example those in rural areas) and this can further perpetuate health inequalities – delaying diagnosis /treatment.
- Travel can still be a burden to patients (some patients in the Republic access treatment that is 2 hours away); many cancer patients are older and mobility may be a problem for them, especially if they have to rely on public transport from rural areas; and
- Centralised services can in some cases take skills away from local hospitals in terms of diagnosing and keeping updated with cancer developments.

## 7. Conclusion

Cancer currently affects one in three people and is a main cause of death across Ireland. As the incidence of cancer is likely to increase alongside our aging population, this is placing greater demands on cancer services. Whilst advances in treatments and drugs have increased the cancer survival rate, the costs associated with treating cancer are substantial.

In the last decade, cancer services in Northern Ireland and the Republic of Ireland have been reconfigured. Specialist cancer services are centralised at a number of hospital sites which incorporate cancer units (as in Northern Ireland) or specialised centres (as is the case in the Republic of Ireland). Northern Ireland also has a regional cancer centre for specialist care. Whilst treatment involves a level of travel for patients across the island, care is also provided on a local basis through primary and community care services, and other supports such as charitable organisations.

Both jurisdictions have a Cancer Control Programme in place and a range of preventative and public health strategies to help reduce the burden of cancer amongst the general population. In addition, there is on-going cross border collaboration in terms of cancer care and treatment. Current arrangements enable patients to cross the border to access cancer services in the other jurisdiction when deemed appropriate. In addition, the Cancer Consortium also provides cross jurisdictional collaborative opportunities in the field of cancer for academic researchers, policy makers and clinicians.