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# Research and Information Service Research Paper

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## Cancer: Northern Ireland

This research paper provides an overview of cancer in Northern Ireland. This includes information about:

- cancer statistics;
- policy developments;
- service commissioning;
- screening, care pathways and types of treatment;
- accessibility to hospital treatment across Northern Ireland, and,
- overall performance of Health and Social Care Trusts against Ministerial waiting time targets for cancer.



## Key Points

- Cancer is the **leading cause of death** in Northern Ireland, with 4,255 deaths reported in 2015. The most common types of cancer diagnosed are breast, lung, bowel, and prostate cancers. This group of cancers are sometimes referred to as the “big four”.
- Over 87,000 people in Northern Ireland are living with a diagnosis of cancer in the last 23 years. By 2020, almost **one in two** people will get cancer at some point in their lives.
- Advances in cancer care and treatment mean more people are now **surviving cancer**. One-year net survival for both sexes is 70% and five-year net survival is 55%.
- There are **three main cancer policies** in Northern Ireland. Each lists a number of recommendations or standards to be met. However, the **absence of formal performance reviews** means it is **not possible** to assess how effective those strategies have been.
- All jurisdictions in the UK and Republic of Ireland have, or are in the process of, updating their cancer strategies. The exception is Northern Ireland, which published its strategy **almost ten years ago**. Given the reform of the health and social care system and changes in cancer provision, several local organisations have called for an updated cancer strategy.
- The main cancer treatments include surgery, radiotherapy and drug therapies (such as chemotherapy). Data is unavailable regarding how much Northern Ireland’s healthcare budget is spent on cancer provision, nor how many patients are receiving these treatments. Hence, it is difficult to determine whether services are being **targeted appropriately**.
- Cancer is diagnosed via a staging process. However, **45%** of cancer patients in Northern Ireland are **diagnosed at the later stages** – namely stage three or four. This is when cancer is **far more difficult to treat**. This impacts on patient quality of life and survival rates.
- **None** of the three Ministerial cancer waiting time targets have been achieved in several years. One target has never been achieved – **8 years after its inception**. As demand for cancer care increases, this raises questions like why do these unachievable targets remain in place, and what actions are being taken to improve waiting times?
- Although cancer care is now more centralised within Trusts, there are workforce issues. For example, GPs – the gatekeepers to primary care, are currently **under severe workload and staffing pressures**, and several local practices have closed. There are delays with diagnostic tests. There is also a **shortage of radiologists** (doctors who specialise in diagnosing diseases like cancer) and one quarter of radiology posts are unfilled in Northern Ireland. These issues have led to **diagnostic delays** for cancer patients.
- There are other disparities for patients in terms of **access to treatments and travel times** for more specialised treatments – especially for patients from **rural areas**. **Inequalities** also exist, with the overall incidence of cancer much higher among the most deprived than the least deprived groups in society.

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## 1. Introduction

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 can cause a cancerous (malignant) lump or tumour to form<sup>1</sup> which destroys healthy tissue. Cancer cells can be spread by blood and lymphatics to other parts of the body.

Cancer differs from most other diseases in that it can develop at any stage in life and in any organ in the human body. There are over 200 types of cancer; most are named according to the organ or type of cell in which the cancer originates.<sup>2</sup> Some cancers are more common than others.

It is not known why someone may develop cancer - but certain factors can increase the risk. This could include for example, age, lifestyle, diet, hormones, genetic history, the environment (e.g. exposure to toxins, chemicals or sunlight), and inflammation.

## 2. Statistics for Northern Ireland

- Cancer is the leading cause of death in Northern Ireland.<sup>3</sup>
- Apart from skin cancer, the most common types of cancer diagnosed are breast, lung, bowel, and prostate cancers.<sup>4</sup> These cancers are sometimes referred to as the “big four”.
- By December 2015, there were over 87,000 people living in Northern Ireland who had been diagnosed with some type of cancer in the last 23 years.<sup>5</sup>
- Incidence of cancer is rising.<sup>6</sup> 7,200 cancer cases (excluding non-malignant skin cancers)<sup>7</sup> were reported in Northern Ireland in 2004, increasing to 9,250 cases in 2015.<sup>8</sup> This trend is expected to continue due to the ageing population, and to preventable risk factors such as obesity and smoking.
- Cancer incidence is 15% higher in the most deprived communities compared to the Northern Ireland average, and 8% lower in the least deprived communities.<sup>9</sup>
- By 2020, almost one in two people will get cancer at some point in their lives.<sup>10</sup>

<sup>1</sup> Cancer Research UK website 'What is cancer' <http://www.cancerresearchuk.org/about-cancer/what-is-cancer> Website accessed 17.5.17

<sup>2</sup> Macmillan Cancer Support Website. Cancer and cell types. <http://www.macmillan.org.uk/information-and-support/understanding-cancer/cancer-and-cell-types.html> Website accessed 18.5.17

<sup>3</sup> NISRA website. Registrar General Annual Report <https://www.nisra.gov.uk/statistics/births-deaths-and-marriages/registrar-general-annual-report> Website accessed 13.5.17

<sup>4</sup> Northern Ireland Cancer Registry. All Cancers Factsheet <https://www.qub.ac.uk/research-centres/nicr/CancerInformation/official-statistics/BySite/all-cancers/> Website accessed 13.5.17

<sup>5</sup> Cancer prevalence data provides a snapshot of people living with cancer. Data from the Northern Ireland Cancer Registry. Prevalence as at 31 December 2015. All cancers combined. Website accessed 18.5.17

<sup>6</sup> Incidence rate is the number of new cancers diagnosed in a specified population, usually per 100,000 people, during a year.

<sup>7</sup> According to the Northern Ireland Cancer Registry, incidence of non-malignant skin cancers tends to be excluded from cancer survival statistics because of concerns about the completeness of registration and due to its low fatality rates.

<sup>8</sup> Northern Ireland Cancer Registry. Incidence Trend <https://www.qub.ac.uk/research-centres/nicr/CancerInformation/official-statistics/BySite/All-Cancers-excl-NMSC/> Website accessed 18.5.17

<sup>9</sup> Northern Ireland Cancer Registry (2017) Cancer incidence and survival statistics for NI 2011-2015

<sup>10</sup> Macmillan Cancer Support. Cancer mortality trends: 1992–2020.

- The number of deaths from cancer is also rising. In 2005, there were 3,726 reported deaths from cancer and 4,255 reported deaths in 2015.<sup>11</sup> Lung cancer is the most common cancer-related death. This is largely linked to the number of people who smoke or have previously smoked.<sup>12</sup>
- More people are surviving cancer. The most recent cancer survival data - available from 2006-2010<sup>13</sup> shows that one-year net survival for both sexes is 70% and five-year net survival is 55%.<sup>14</sup> However survival rates are influenced by a number of factors, such as:

- The type of cancer
- The stage of diagnosis; diagnostic delay
- The individual - awareness of possible symptoms; other health conditions
- Socio-economic status and levels of deprivation
- Access to effective and timely treatments and medical care

- Furthermore, research also suggests that Northern Ireland has lower survival rates when compared to the European average, particularly for colon, ovary, kidney, stomach and lung cancers.<sup>15</sup>

### 3. Cancer Policies in Northern Ireland

The Department of Health (DoH) in Northern Ireland (formerly the Department of Health, Social Services and Public Safety) sets the overall policy direction in relation to cancer care. Several Departmental policies encourage healthy lifestyle behaviours that may help play a part in *cancer prevention* - such as encouraging healthy eating and physical activity, and reducing alcohol consumption and smoking.<sup>16</sup>

<sup>11</sup> Northern Ireland Cancer Registry (2015) All Cancers excluding Non-Melanoma Skin Cancer (NMSC): Mortality statistics: 1993-2015. <http://www.qub.ac.uk/research-centres/nicr/CancerInformation/official-statistics/BySite/All-Cancers-excl-NMSC/> Website accessed 17.5.17

<sup>12</sup> Cancer Focus Northern Ireland website. <https://cancerfocusni.org/cancer-info/types-of-cancer/lung-cancer/> Accessed 17.5.17

<sup>13</sup> More recent survival rates - for example between 2010-2015 are not available because not all patients diagnosed in that timeframe would have had five or ten years' follow-up.

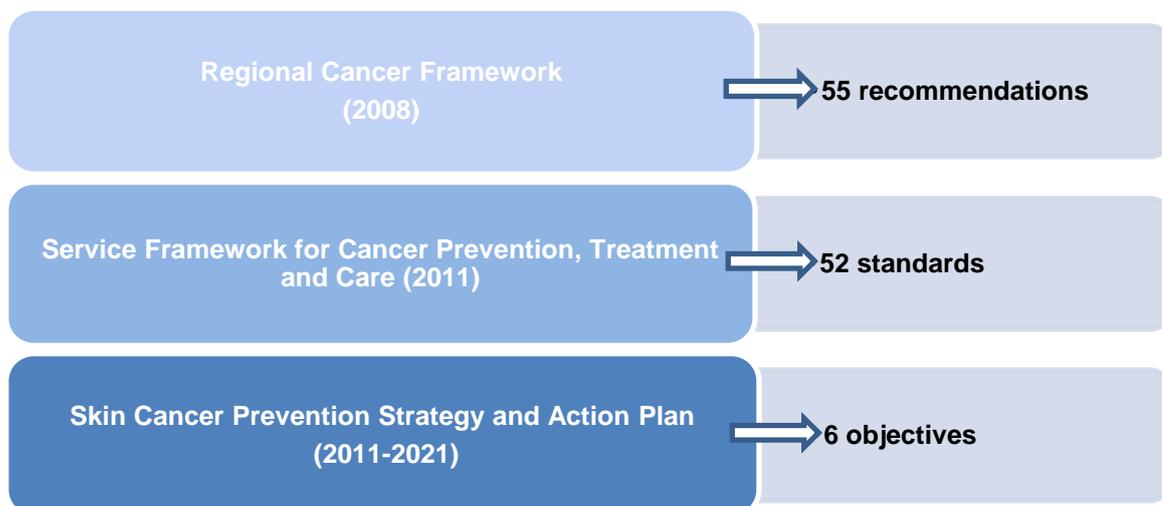
<sup>14</sup> Data obtained from E. Morgan, Northern Ireland Cancer Registry. Data received 5.6.17

<sup>15</sup> Study based on 29 countries. De Angelis, R et al. (2014) Cancer survival in Europe 1999–2007 by country and age: results of EURO CARE-5—a population-based study, *The Lancet, Oncology*, Volume 15, No. 1, p23–34.

<sup>16</sup> See for example the Department of Health (NI) website <https://www.health-ni.gov.uk/> policies such as *Making Life Better 2013-2023* <https://www.health-ni.gov.uk/publications/making-life-better-strategy-and-reports>

At the time of writing, there are **three key policies**<sup>17</sup> specifically focused on cancer in Northern Ireland (Figure 1).

Figure 1. Cancer policies (Northern Ireland)



### 3.1 Current cancer strategy (2008)

Northern Ireland's current cancer strategy is the Regional Cancer Framework, which was published in 2008. Its aim is to reduce the burden of cancer on the population.<sup>18</sup> It also seeks to: *"make detailed recommendations for a programme of action for cancer services up to 2008; outline recommendations for the development of cancer services up to 2015; and for the strategic direction of cancer services up to 2024."*<sup>19</sup>

The framework contains information on policy developments, cancer statistics, prevention, screening, living with cancer, treatments and staffing, in addition to 55 recommendations grouped under 6 themes. The themes are: prevention, early detection and screening; improving the experience of people affected by cancer; improving access to diagnosis and treatment; research information and audit; making it happen; and equality impact assessment.

### 3.2 Gaps in the 2008 cancer strategy

The Regional Cancer Framework states that it will be supported by a number of other documents (Table 1). However, some of these documents are not publically available.

<sup>17</sup> Available from the Department of Health (NI) website <https://www.health-ni.gov.uk/> Website accessed 21.5.17

<sup>18</sup> Department of Health (NI), Regional Cancer Framework (2008) A Cancer Control Programme for Northern Ireland, p5. Available at: [www.cancerni.net/files/cancer\\_control\\_programme.pdf](http://www.cancerni.net/files/cancer_control_programme.pdf)

<sup>19</sup> Department of Health (NI), Regional Cancer Framework (2008), p6.

Table 1. Documentation to support the Regional Cancer Framework

Regional Cancer Framework supporting documentation	Current status
"An <b>action plan will be developed</b> ... which will include a range of targets by which we can measure progress against the recommendations of the Cancer Control Programme." <sup>20</sup>	Action Plan not publically available <sup>21</sup>
" <b>Over the coming months</b> the framework will be complemented by a <b>document</b> setting out <b>clear and measurable standards</b> for the delivery of cancer services." <sup>22</sup>	Standards (in the form of the Service Framework) were not published until 2011. <sup>23</sup>
"Progress against the final recommendations will be assessed <b>and published</b> within 3 years of publication with a <b>formal review of recommendations by 2011</b> ." <sup>24</sup>	No formal review published.
"The RQIA <sup>25</sup> will provide independent assessment of cancer services against national standards and the Quality Standards for Health and Social Care." <sup>26</sup>	It is unclear to what extent this information has been collected and if it is in the public domain.

Given the absence of formal reviews and performance data, it is **not possible** to assess how the Department of Health's strategy has progressed against the 55 recommendations.

### 3.3 Service Framework for Cancer Prevention, Treatment and Care (2011)

Following the cancer strategy (the Regional Framework) a Service Framework for Cancer Prevention, Treatment and Care was published by the Department of Health in 2011.<sup>27</sup> Its aim is to define measurable evidence-based standards regarding the delivery of cancer care. It contains 52 detailed standards, with performance indicators and dates for when targets should be achieved.

### 3.4 Gaps in the Service Framework

The Service Framework also has a number of limitations. For example, it states, "*This is a three year service framework and was not designed to be fully comprehensive of all cancers*".<sup>28</sup> Given the limited timeframe, it is not known if the standards are still applicable - as **no updated framework** post 2013-14 is in place. The Framework also states "*performance indicators and targets will be reviewed and adjusted as necessary, in the light of the current Budget settlement for 2011-12 to 2013-14*".<sup>29</sup> Information

<sup>20</sup> Department of Health (NI), Regional Cancer Framework (2008), p5.

<sup>21</sup> Cancer Research UK (2016) Where next for cancer services in Northern Ireland? p27.

<sup>22</sup> Department of Health (NI), Regional Cancer Framework (2008), p5.

<sup>23</sup> Department of Health (NI), Service Framework for Cancer Prevention, Treatment and Care (2011).

<sup>24</sup> Department of Health (NI), Regional Cancer Framework - A Cancer Control Programme for Northern Ireland, p6.

<sup>25</sup> Regulation and Quality Improvement Authority. Available online at: <https://www.rqia.org.uk/> Website accessed 21.5.17

<sup>26</sup> Department of Health (NI) Regional Cancer Framework - A Cancer Control Programme for Northern Ireland, p45.

<sup>27</sup> Available online at: <https://www.health-ni.gov.uk/publications/cancer-prevention-treatment-and-care-service-framework-documents> Website accessed 21.5.17

<sup>28</sup> Department of Health (NI), Service Framework for Cancer Prevention, Treatment and Care (2011) p47.

<sup>29</sup> Department of Health (NI), Service Framework for Cancer Prevention, Treatment and Care (2011) p4.

about whether the indicators and targets were reviewed or adjusted as a result of the previous budget settlements is also not known or publically available.

Furthermore, it is unclear if the standards in the Service Framework were achieved, as **no performance data is publically available**. The Framework also states that there would be an **implementation plan** to support the standards, however this is also **not publically available**, nor is any type of **formal review**.

### 3.5 Skin Cancer Prevention Strategy and Action Plan (2011-2021)

The Skin Cancer strategy was also published in 2011. Skin cancer is now the most common form of cancer in Northern Ireland.<sup>30</sup> There are over 4,000 new cases diagnosed annually and the number of cases has doubled over the last 20 years. In 2015, 3,830 cases of non-malignant melanoma, which is rarely fatal, were diagnosed. In the same year, 402 cases of malignant melanomas - the most serious type of skin cancer, were diagnosed.<sup>31</sup>

The Skin Cancer strategy highlights various types of skin cancer, factors that increase the risk of developing the disease (e.g. over exposure to UV radiation, having fair skin types, the increase in uptake of low cost sun holidays, use of tanning salons, and climate change), and measures that can be adopted to reduce these risks.

The strategy contains 3 targets to be achieved by 2016, namely:<sup>32</sup>

1. a 10% increase in the number of men taking protective measures in the sun;
2. to increase by 5% the number of people who check their skin for cancer one per month or more and
3. to reduce by 30% the proportion of 16-25 year olds currently using sunbeds.

In addition, the strategy contains 6 objectives to be met. These include for example, increasing public awareness of the dangers of sun exposure, reducing sunbed use and encouraging earlier detection.<sup>33</sup> Yet timescales attributed to the objectives are non-specific (described as, for example “ongoing” or “long-term”), and thus **cannot be easily measured**.

<sup>30</sup> Skin Cancer Prevention Strategy and Action Plan (2011-2021) Available online at:

<https://www.health-ni.gov.uk/publications/skin-cancer-prevention-strategy>, p 5. Website accessed 20.5.17

<sup>31</sup> Northern Ireland Cancer Registry. Available online at: <https://www.qub.ac.uk/research-centres/nicr/CancerInformation/official-statistics/BySite/#> Website accessed 21.5.17

<sup>32</sup> Skin Cancer Prevention Strategy and Action Plan (2011-2021) Available online at:

<https://www.health-ni.gov.uk/publications/skin-cancer-prevention-strategy>, p 37. Website accessed 21.5.17

<sup>33</sup> Skin Cancer Prevention Strategy and Action Plan (2011-2021) Available online at:

<https://www.health-ni.gov.uk/publications/skin-cancer-prevention-strategy>, pp38-40. Website accessed 22.5.17

### 3.6 Gaps in the Skin Cancer Strategy

Similar to the other cancer policies, data on whether the skin cancer targets and objectives have been met are **unpublished** and thus impossible to evaluate. The strategy also stated that “A formal review will be undertaken after five years to allow an in-depth assessment of progress made against the objectives and targets”.<sup>34</sup> This formal review (due 2016) has also **not been published**.

Each of the three cancer policies highlight that more transparency is needed; and for supporting documents (e.g. implementation plans, action plans and reviews) to be published. This will increase accountability, demonstrate progress to the commitments, establish the evidence base for what is effective in terms of cancer care, and show where improvements are still required.

### 3.7 Cancer strategies - UK and Republic of Ireland

Different cancer strategies exist across the UK and the Republic of Ireland (Table 2).

Table 2. Main cancer strategies in the UK and Republic of Ireland

Jurisdiction	Main cancer strategy or policy	Publication date
England	Achieving world-class cancer outcomes: a strategy for England 2015-2020 <sup>35</sup>	2015
Wales	Cancer Delivery Plan for Wales 2016 to 2020 <sup>36</sup>	2016
Scotland	Beating Cancer: Ambition and Action <sup>37</sup>	2016
Northern Ireland	Regional Cancer Framework - A Cancer Control Programme for Northern Ireland <sup>38</sup>	2008
Republic of Ireland	A Strategy for Cancer Control in Ireland <sup>39</sup> **A new National Cancer Strategy is due in 2017	2006**

All jurisdictions shown in Table 2 have updated, or, are in the process of updating their cancer strategies - with the exception of Northern Ireland where the strategy was published **almost ten years ago**. This had led to several cancer organisations in Northern Ireland to call for a revised local strategy. This, they argue, coupled with the

<sup>34</sup> Skin Cancer Prevention Strategy and Action Plan (2011-2021) Available online at:

<https://www.health-ni.gov.uk/publications/skin-cancer-prevention-strategy>, p41. Website accessed 22.5.17

<sup>35</sup> Independent Cancer Taskforce. Achieving world-class cancer outcomes: a strategy for England 2015-2020. Available online at: <http://www.necn.nhs.uk/achieving-world-class-cancer-outcomes-a-strategy-for-england-2015-2020-in-july-2015/> Website accessed 22.5.17

<sup>36</sup> Welsh Government. Cancer Delivery Plan for the NHS to 2020 <http://gov.wales/topics/health/nhswales/plans/cancer-plan/?lang=en> Website accessed 20.5.17

<sup>37</sup> The Scottish Government. Available online at: <http://www.gov.scot/Publications/2016/03/9784> Website accessed 22.5.17

<sup>38</sup> Department of Health (Northern Ireland) Regional Cancer Framework - A Cancer Control Programme for Northern Ireland. Available online at: [www.iccp-portal.org/sites/default/files/plans/cancer\\_control\\_programme.pdf](http://www.iccp-portal.org/sites/default/files/plans/cancer_control_programme.pdf) Website accessed 22.5.17

<sup>39</sup> Department of Health (Ireland) Strategy for Cancer Control in Ireland. Available online at:

<http://health.gov.ie/blog/publications/strategy-for-cancer-control-in-ireland/> Website accessed 22.5.17

current reforms in the health and social care system (discussed below), is a timely opportunity for the development of **a new cancer strategy**.<sup>40,41</sup>

The Department of Health was contacted for a view on whether a new cancer strategy would be developed for the purposes of this paper, but no response was received.

#### 4. Commissioning of cancer services

The Health and Social Care Board is responsible for commissioning cancer services for the local population.<sup>42</sup> The Board is accountable to the Department of Health. Every year, the Board, in association with the Public Health Agency, publishes a general Commissioning Plan<sup>43</sup> whereby five Local Commissioning Groups commission services from each of the local Health and Social Care Trusts.

In 2016/17, the health and social care budget allocated to the Department of Health in Northern Ireland was approximately £4.88 billion.<sup>44</sup> This is nearly half (46%) of the total Northern Ireland Executive budget.<sup>45</sup>

Cancers services are purchased through various healthcare funding streams rather than a single cancer budget. This is unlike other health care systems - such as Wales, which has a specific cancer budget; cancer care accounts for 7% of their total budget.<sup>46</sup>

As it remains unknown how much of the Northern Ireland healthcare budget is spent on cancer,<sup>47</sup> it is difficult to determine whether local services are being targeted appropriately.

Furthermore, there are increasing pressures on the health and social care budget. Over the past number of years, the Department of Health has commissioned several reviews to bring about changes in the current healthcare system and to make it more efficient and effective. These include:

- *Transforming Your Care* (2011)<sup>48</sup>;
- *Right Time, Right Place* (2014)<sup>49</sup>, and
- *Systems Not Structures - Changing health and social care* (2016).<sup>50</sup>

Altogether, the reviews make over 120 recommendations to reform the provision of care and services in Northern Ireland. Some of the recommendations, coupled with

<sup>40</sup> Cancer Focus Northern Ireland. A fresh Vision for Cancer in Northern Ireland.

<sup>41</sup> Cancer Research UK (2016) Where next for cancer services in Northern Ireland? p.29

<sup>42</sup> Health and Social Care Board website <http://www.hscboard.hscni.net/> Website accessed 20.5.17

<sup>43</sup> Health and Social Care Board Commissioning Plan 2016/17 Available online at: <http://www.hscboard.hscni.net/publications/commissioning-plans/> Website accessed 19.5.17

<sup>44</sup> Northern Ireland Executive. Budget 2016-17. <https://www.northernireland.gov.uk/publications/budget-2016-17> p40.

<sup>45</sup> Bengoa Report (2016) Systems, Not Structures - Changing Health and Social Care, p33

<sup>46</sup> Stats Wales (2016) NHS expenditure percent of total by budget category and year.

<sup>47</sup> Personal correspondence between author and former DHSSPS. Response dated 21.8.13

<sup>48</sup> Compton J, et al. (2011) Transforming Your Care. Available online at: <https://www.health-ni.gov.uk/topics/health-policy/transforming-your-care> Website accessed 28.5.17

<sup>49</sup> Donaldson, L. (2014) Right Time, Right Place. Available online at: <https://www.health-ni.gov.uk/topics/health-policy/donaldson-report> Website accessed 28.5.17

<sup>50</sup> Bengoa, R. et al. (2016) Systems, Not Structures - Changing Health and Social Care. Available online at: <https://www.health-ni.gov.uk/publications/systems-not-structures-changing-health-and-social-care-full-report> Website accessed 26.5.17

increased budgetary restrictions, are likely to have implications for the provision of cancer services in the future.

#### 4.1 Other organisations involved in cancer care

Many other organisations also work in partnership to improve care, awareness and our understanding of cancer. Some examples include:

- the RQIA<sup>51</sup> is the independent body responsible for inspecting and ensuring the quality of care by the standards set by the Department of Health. It inspects some cancer services (not secondary care), such as the 5 adult hospices in Northern Ireland
- clinical leadership is provided by NICaN (Northern Ireland Cancer Network)<sup>52</sup>
- cancer awareness campaigns, for example the “Be Cancer Aware” Campaign<sup>53</sup> and screening (see below) are the responsibility of the Public Health Agency,<sup>54</sup>
- official statistics on cancer are provided by NICR (the Northern Ireland Cancer Registry)
- cancer research is being undertaken by academic and charitable research centres.

#### 4.2 Measuring the performance of cancer care and service provision

Performance is measured through standards of care set out in the Service Framework, data held by Trusts, the Regulation and Quality Improvement Agency, and through audit mechanisms such as CaPPs (Cancer Patient Pathway System), peer review sessions for teams treating specific cancers, and waiting time targets. Overall, assessing performance from a scrutiny perspective is difficult as not all information is readily available or in the public domain.

### 5. Cancer screening

Screening involves inviting members of the public who have no symptoms of cancer to be tested. Cancer screening is overseen by the Public Health Agency and testing is free of charge. The tests can help detect signs of cancer at an early stage, or changes that occur before a particular cancer develops (e.g. cervical cancer). However, screening cannot guarantee that cancer will be detected, and sometimes the cancer being screened for will be missed.

There are three national cancer screening programmes aimed at specific age groups currently operating in Northern Ireland as shown in Table 3:<sup>55</sup>

<sup>51</sup> Regulation and Improvement Authority <https://www.rqia.org.uk/> The RQIA is also accountable to the Department.

<sup>52</sup> Northern Ireland Cancer Network <http://www.cancerni.net/>

<sup>53</sup> Public Health Agency, Be Cancer Aware Campaign Website <http://www.becancerawareni.info/what-cancer>

<sup>54</sup> Public Health Agency <http://www.publichealth.hscni.net/>

<sup>55</sup> Cancer Focus Website. Screening Programmes. Available online at <https://cancerfocusni.org/cancer-info/screening-programmes/> Website accessed 28.5.17

Table 3. Cancer screening programmes Northern Ireland

Breast cancer	For women aged 50-70; mammogram offered every 3 years
Cervical cancer	For women aged 25-64; smear offered every 3 years, and for those aged 50-64, every 5 years
Bowel cancer	For men and women aged 60-74 years; test offered every 2 years via a home test kit

Screening programmes for other cancers have not been set up for several reasons such as the unreliability of some testing methods, risks to patients, and cost effectiveness.<sup>56</sup>

## 6. Diagnosis

Early diagnosis is crucial to improving patient survival rates for many forms of cancer. However, some cancers, such as breast and skin cancers, have specific symptoms; others, such as pancreatic cancer, present with non-specific symptoms and may be more difficult to detect early.

The progression of cancer is usually determined through a staging and grading process and is discussed in the literature elsewhere. The staging process can help determine the size of a cancer, how far it has grown, and the type of treatment(s) needed.<sup>57</sup>

Yet data from the Northern Ireland Cancer Registry shows that between 2011-2015, nearly half (45%) of cancer patients in Northern Ireland with a known cancer stage were diagnosed at a later stage – namely stage three or four (20% were diagnosed at stage 3, and 25% were diagnosed at stage 4).<sup>58</sup> At these stages, cancer is far more difficult to treat. This negatively impacts on patient quality of life and survival rates.<sup>59</sup>

Given the lateness of diagnosis for some cancer types, in a recent major report, Cancer Research UK has stated that there is scope to detect and diagnose cancer earlier in Northern Ireland.<sup>60</sup>

## 7. Patient pathways

Integrated health and social care services are provided to the local population by six Health and Social Care Trusts. They are divided into 5 geographical areas - the

<sup>56</sup> Cancer Research UK Website. Why isn't screening available for all cancers? Available online at:

<http://www.cancerresearchuk.org/about-cancer/screening/why-isnt-screening-available-for-all-cancers>

<sup>57</sup> Cancer Research UK Stages of cancer <http://www.cancerresearchuk.org/about-cancer/what-is-cancer/stages-of-cancer>

<sup>58</sup> Data received from Gerard Savage Northern Ireland Cancer Registry on 15.6.2017.

<sup>59</sup> Department of Health (NI), Service Framework for Cancer Prevention, Treatment and Care (2011), p63

<sup>60</sup> Cancer Research UK (2016) Where next for cancer services in Northern Ireland? p40

Northern, Southern, South Eastern, Western, and Belfast Trust. The sixth trust is the Northern Ireland Ambulance Service serving across all trust areas.

The patient pathway is the route patients take from their first contact with a medical professional, through to referral and completion of their treatment.

Patient pathways for cancer diagnosis, treatment and management are complex and require the involvement of multi-disciplinary teams. The electronic CaPPS system is in place to monitor cancer patient waiting times for diagnosis and treatment, and this information is used routinely to assist medical professionals in rapid decisions on the patient's care plan."<sup>61</sup>

Cancer services vary by Trust area and are delivered by a range of statutory, voluntary and charitable organisations.<sup>62</sup> The Department of Health was contacted for a full list of cancer services funded by the HSC budget by Trust area, but this information was not received. Nevertheless, a directory of the types of services available is provided on the Cancer Survivorship website for Northern Ireland.<sup>63</sup>

## 7.1 Primary Care

The first point of contact for the majority of people in relation to cancer care is likely to be in primary care via their general practitioner (GP). However sometimes a cancer diagnosis is made as a result from a patient attending A&E (secondary care).<sup>64</sup>

If cancer is suspected, the GP will make an urgent referral against set criteria to see a specialist in a hospital setting.<sup>65</sup> These are known as 'red flag' or 'suspect cancer' referrals. GPs can also refer patients directly for investigative tests to speed up the diagnostic process, but this is reported to be variable in Northern Ireland at present. In addition, there is a **growing number of people having to wait for such tests**.<sup>66</sup>

There are currently around 1,300 GPs providing care in Northern Ireland across 350 GP practices (Figure 2).<sup>67</sup>

<sup>61</sup> Department of Health website ICT programme. Online at: <https://www.health-ni.gov.uk/articles/gmgr-ict-programme>

<sup>62</sup> See for example, the Marie Curie Website - Cancer support organisations. Available online at: <https://www.mariecurie.org.uk/help/support-directory/cancer-support-organisations> Website accessed 26.5.17

<sup>63</sup> Cancer Survivorship Website for Northern Ireland. Available online at: <http://survivorship.cancerni.net/> Website accessed 5.6.17

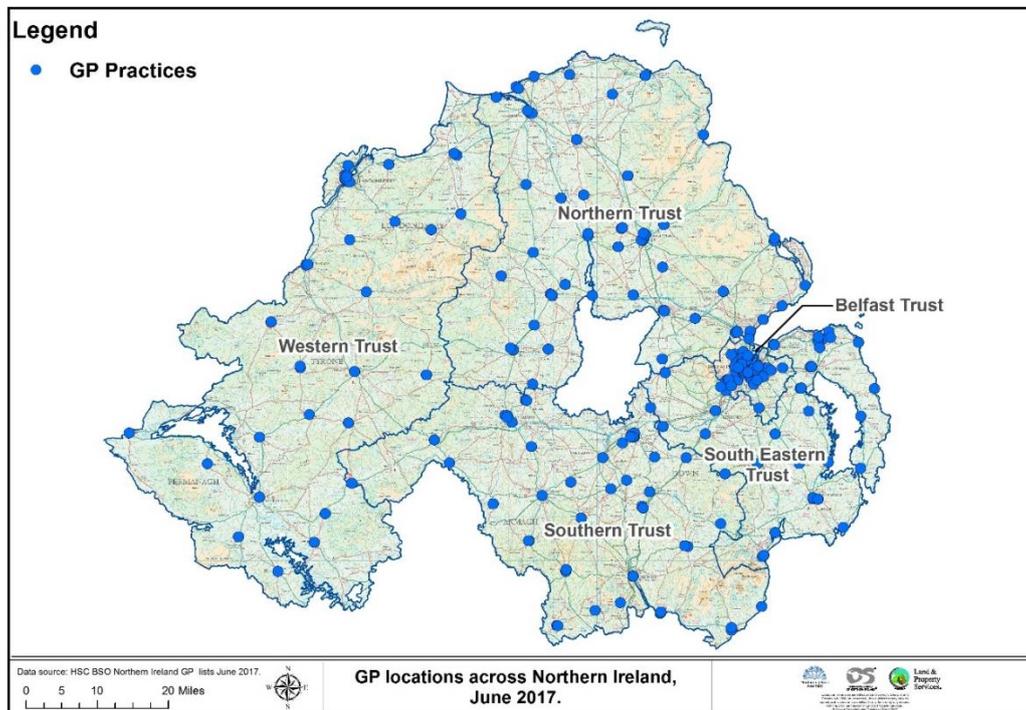
<sup>64</sup> Abel, G.et al. (2017) Emergency diagnosis of cancer and previous general practice consultations: insights from linked patient survey data. British Journal of General Practice. Available online at: <http://bjgp.org/content/early/2017/04/24/bjgp17X690869>

<sup>65</sup> Northern Ireland Cancer Network. Northern Ireland Referral Guidance for Suspected Cancer – Red Flag Criteria (2012) <http://www.cancerni.net/content/northern-ireland-referral-guidance-suspected-cancer-%E2%80%93-red-flag-criteria>

<sup>66</sup> Cancer Research UK Cambridge Institute. Improving care for cancer patients in Northern Ireland. Available online at: <http://www.cambridgecancer.org.uk/news/latest-news/improving-care-cancer-patients-northern-ireland> Website accessed 28.5.17

<sup>67</sup> Health and Social Care Online GP services. Available online at: <http://online.hscni.net/family-practitioners/general-practitioners-gps/> Website accessed 6.6.17

Figure 2. Map of GP practice locations across Northern Ireland



Northern Ireland has the lowest number of GPs per head of the population in the United Kingdom. Furthermore, a recent report by the British Medical Association (BMA) indicates that **local GP practices are in crisis**, citing unsustainable workforce, workload and funding pressures.<sup>68</sup>

Giving the increasing strains, several GP practices have already closed in the last few months and more are expected to close this year. The BMA has warned that practices in rural areas – especially in County Fermanagh (where cancer patients are also furthest from hospital treatment sites), are particularly vulnerable.

In December 2016, hundreds of local GPs signed undated resignation letters which could lead to several GP practices being privatised. If this happens, this could translate into their patients paying for consultations<sup>69</sup> and possibly as a consequence, delaying seeking treatment.

<sup>68</sup> British Medical Association. General Practice in Crisis – a report on primary care in Northern Ireland, p3.

<sup>69</sup> Belfast Telegraph (March 2017) Northern Ireland GP practices 'face privatisation' <http://www.belfasttelegraph.co.uk/news/northern-ireland/northern-ireland-gp-practices-face-privatisation-35566998.html> <http://www.belfasttelegraph.co.uk/news/northern-ireland/northern-ireland-gp-practices-face-privatisation-35566998.html> Website accessed 5.6.17

Given that GPs have a vital role to play in screening, diagnosis and the long-term management of cancer, the current GP shortage and rising levels of demand for GP care has implications for access to timely cancer diagnosis and treatment.

## 7.2 Secondary Care

Patients with a diagnosis of cancer are usually treated in a hospital setting. This is known as secondary care. The main cancer treatments include surgery, radiotherapy<sup>70</sup> and drug therapies (such as chemotherapy).

## 7.3 Where are secondary care services for cancer located?

In 1996, the first major review of cancer services in Northern Ireland was undertaken. This was known as the *Campbell Report*.<sup>71</sup> It recommended a new joined-up model for cancer services, based on a regional cancer centre and supporting cancer units. That model largely reflects the location of cancer units today.

At present, hospital sites for the care and treatment of cancer are as follows (Figure 3):

- There are five main cancer units - each located in an acute hospital within the 5 Health and Social Care (HSC) Trusts.<sup>72</sup> Most diagnostic tests, much surgery and an increasing range of chemotherapy are now carried out locally.<sup>73</sup>
- Specialist cancer services are also located within two of the five cancer unit sites:
  - The Northern Ireland Cancer Centre, located at Belfast City Hospital. This regional centre provides specialist treatments for cancer including the most complex tumours, radiotherapy and a regional oncology service.<sup>74</sup>
  - The North West Cancer Centre, located at Altnagelvin Hospital in Londonderry.<sup>75</sup> The building of this cross border centre was completed in 2016 at a cost of £50 million. It is jointly funded by the Health Departments in Northern Ireland and the Republic of Ireland. The centre provides patients in the Western and Northern Trusts and patients from Donegal with radiotherapy services, and a range of other cancer treatments.<sup>76</sup>

<sup>70</sup> Treatment using radiation to inhibit the disease process, especially the destruction of tumours. Radiation may come from an external beam focused on the tumour or small quantities of radioactive material may be inserted directly into the tumour.

<sup>71</sup> DHSS (1996) 'Cancer Services – Investing for the Future'

<sup>72</sup> Excluding the sixth Trust which is the Northern Ireland Ambulance Service Trust

<sup>73</sup> NICAN (2010) National Cancer Peer Review Programme, p10.

<sup>74</sup> Belfast Health and Social Care Trust. Northern Ireland Cancer Centre website. Available online at: <http://belfasttrust-cancerservices.hscni.net/NorthernIrelandCancerCentre.htm> Website accessed 28.5.17

<sup>75</sup> Western Health and Social Care Trust. North West Cancer Centre website <http://www.westerntrust.hscni.net/NorthWestCancerCentre.htm> Website accessed 31.5.17

<sup>76</sup> Western Health and Social Care Trust. Radiotherapy unit – Altnagelvin hospital. Available online at: [www.westerntrust.hscni.net/pdf/RadioTexhibit.pdf](http://www.westerntrust.hscni.net/pdf/RadioTexhibit.pdf)

Figure 3. Hospital cancer treatment sites in Northern Ireland

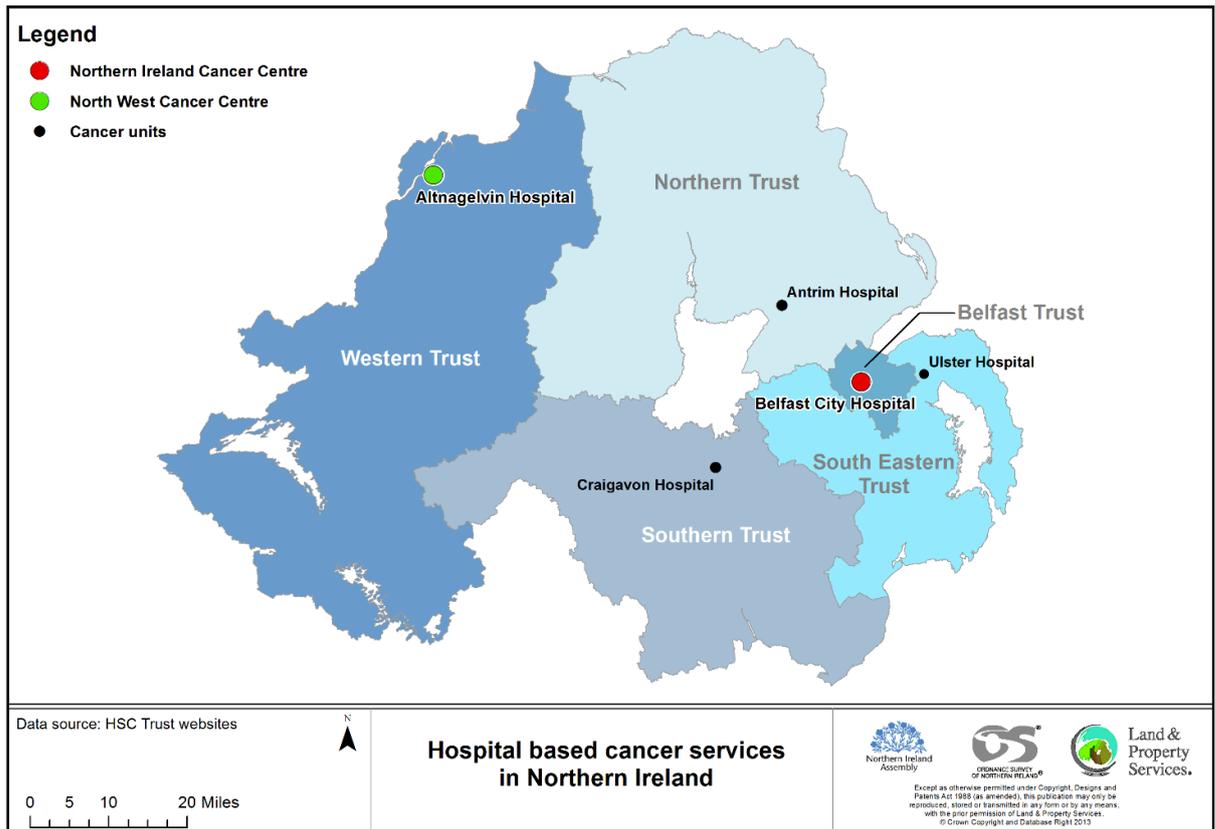
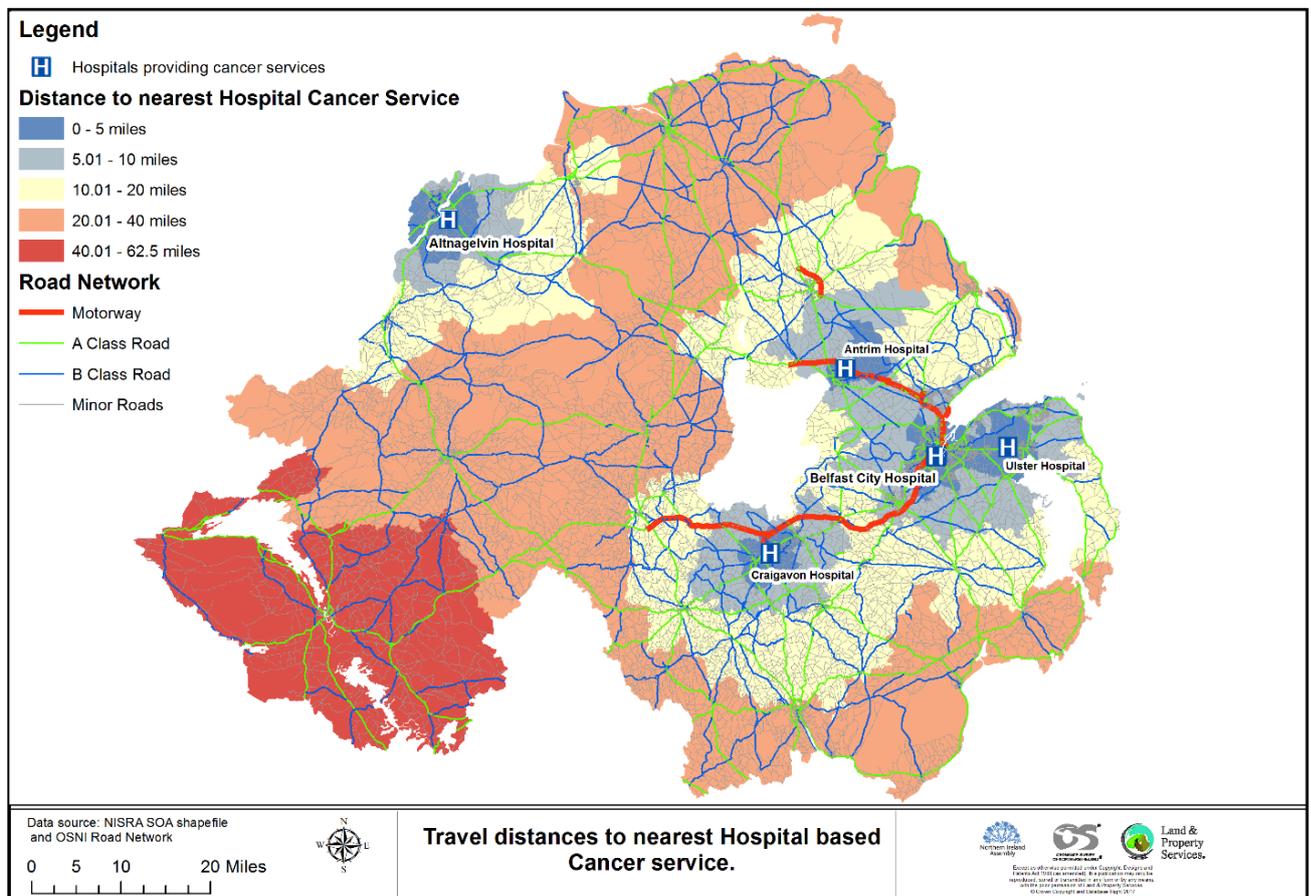


Figure 4 below shows the distance to the nearest cancer unit via the local road network. As can be seen, the majority of cancer services are located in the east of Northern Ireland, with motorways providing a quicker access route for some patients.

Other patients - particularly **those from parts of Fermanagh** (the Western HSC Trust), are subject to **longer travel times** to access cancer treatment. This is partly due to distance from treatment sites; with many patients travelling at least 40-60 miles, and to rurality - where road networks are less developed than other parts of the province. The map highlights the dearth of motorway networks in the north and west of Northern Ireland.

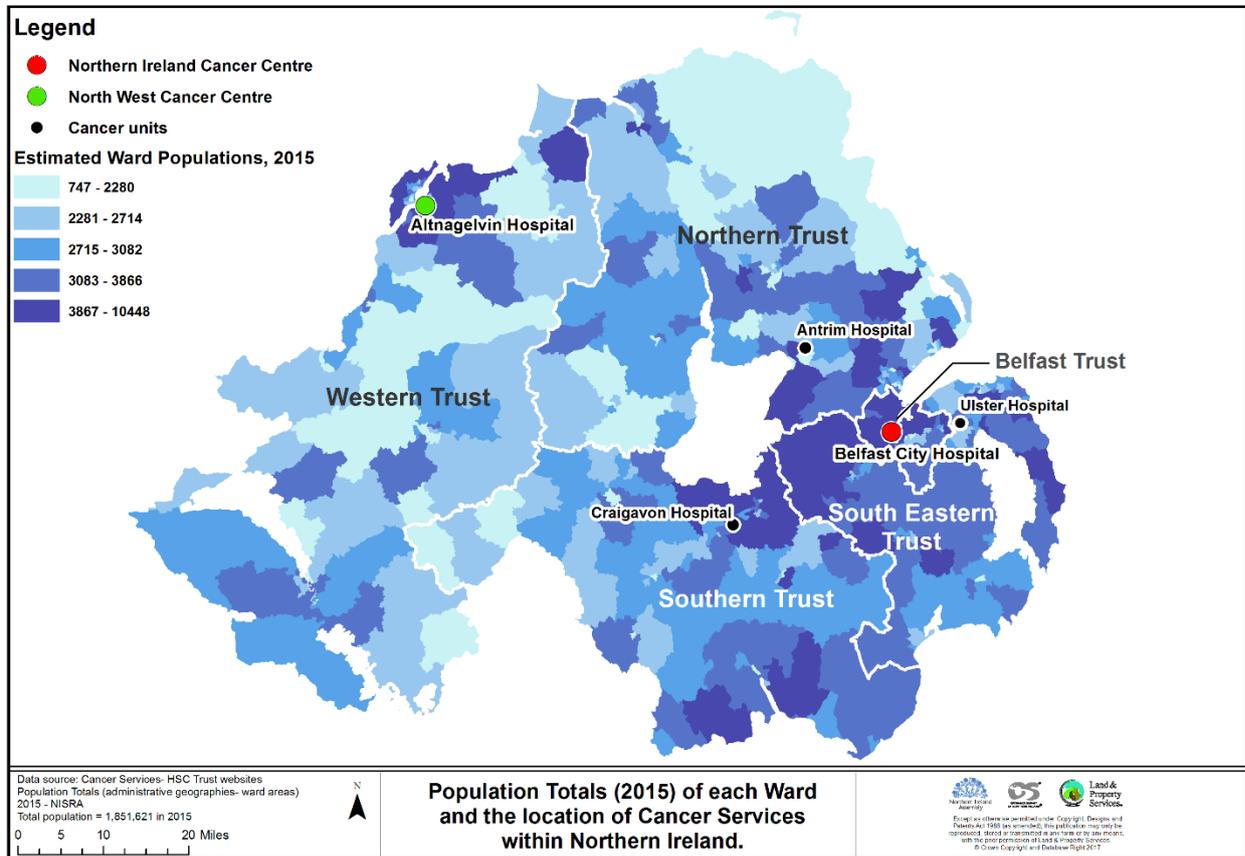
Figure 4. Travel distances to nearest hospital cancer sites in Northern Ireland



It should also be noted that patients will not always be treated in the cancer unit in their local trust, given that some patients will require more specialist treatments provided in the Northern Ireland Cancer Centre in Belfast.

Both of Northern Ireland's cancer centres are located in the two most densely populated geographical areas of Northern Ireland (Figure 5) in Belfast and Londonderry.

Figure 5. Northern Ireland population by Ward in relation to hospital cancer sites



Although exact figures have not been provided by the Department of Health, over half of all cancer patients will require radiotherapy treatment.<sup>77</sup> This treatment is only available at the two cancer centres in either Belfast or Londonderry. With the opening of the new cancer centre in Altnagelvin Hospital in Londonderry, many patients from that surrounding area no longer have to travel to the Regional Cancer Centre in Belfast City Hospital to access radiotherapy.

However, recent media coverage (April 2017) stated that **one quarter** of radiologist posts in Northern Ireland – that is, doctors who specialise in diagnosing and treating diseases (including cancer) using imaging techniques, **were vacant**.<sup>78</sup> This has also led to diagnostic delay.

Data on staffing levels and staff shortages across hospital sites was requested by the author from the Department of Health, but again not provided.

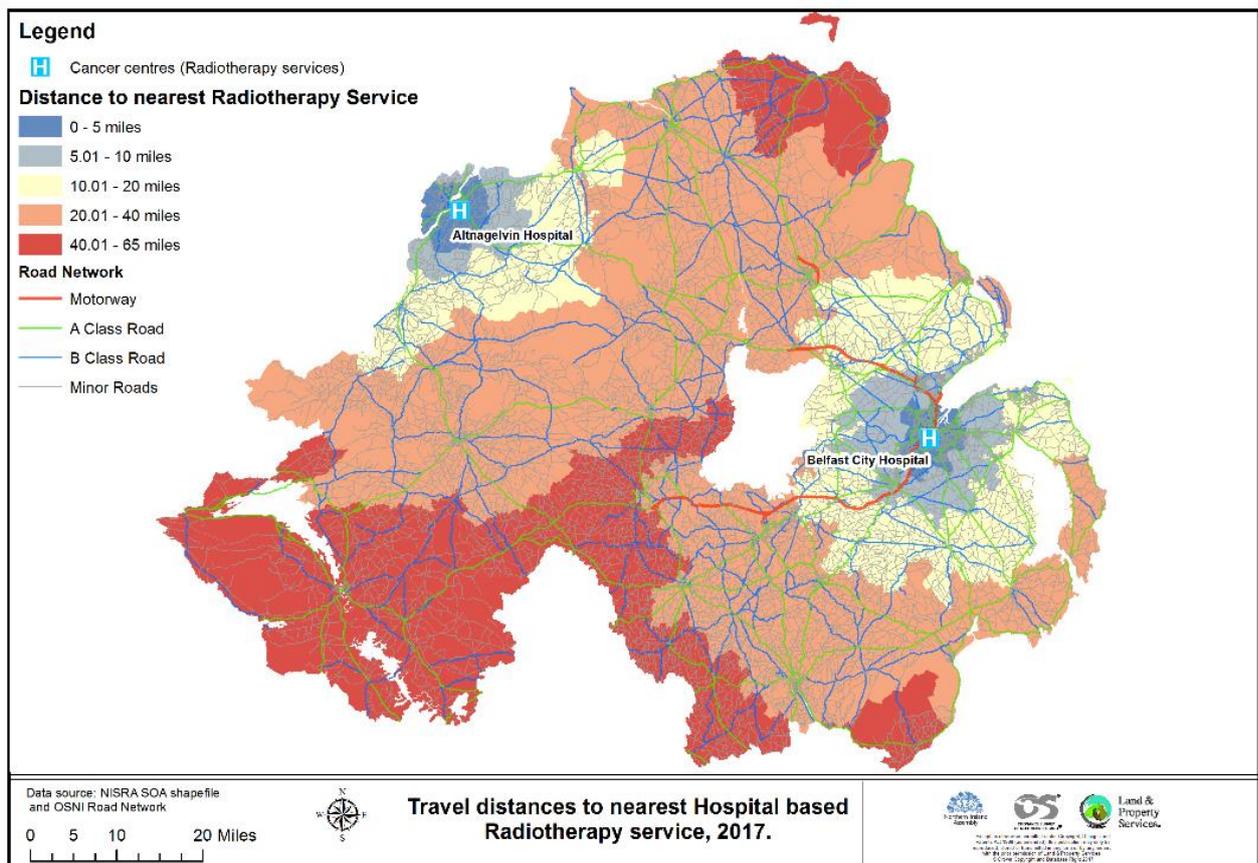
<sup>77</sup> Department of Health (NI), Regional Cancer Framework (2008) A Cancer Control Programme for Northern Ireland.

<sup>78</sup> Connelly, M-L (April 2017) Quarter of radiologist posts in Northern Ireland vacant. Available online at: <http://www.bbc.co.uk/news/uk-northern-ireland-39439218> Website accessed 31.5.17

Coupled with the current problems facing GPs in primary care, there are serious secondary care workforce shortages also impacting on cancer care.

Figure 6 below shows the two cancer centres in Northern Ireland which provide radiotherapy services in relation to approximate travel distances to the nearest centre. Despite the opening of the new cancer centre in Londonderry, some patients still face substantial journeys (in addition to waiting time delays) to access treatment.

Figure 6. Travel distances to nearest radiotherapy service (Cancer Centres)<sup>79</sup>



Again it should be noted that not all patients requiring treatment at a cancer centre will be seen in the nearest centre, as very specialised care is still provided in the Northern Ireland Cancer Centre at Belfast City Hospital.

## 8. Waiting time targets for cancer treatment

Shorter waiting times for cancer can lead to earlier diagnosis and treatment, fewer complications, as well as better experiences for patients and improved outcomes. Cancer patients have many waits; waits to see a GP, waits to see hospital specialists, waits for diagnostic tests and waits for treatment (e.g. surgery). As cancers are so

<sup>79</sup> When interpreting figure 5, it is also important to note that the nearest cancer centre is not always where treatment is delivered as the Northern Ireland Cancer Centre in Northern Ireland still provides the most specialised cancer treatment.

diverse, and the stage of diagnosis varies considerably from patient to patient, little is known about **overall** patient waiting times from referral to completion of treatment.

## 8.1 Cancer waiting times across the UK and Republic of Ireland

Cancer waiting time targets - set by each Department of Health, vary across each jurisdiction:

- Northern Ireland has **three** cancer waiting time performance targets<sup>80</sup>;
- England has **nine** cancer waiting time performance targets<sup>81</sup>;
- Scotland and Wales both have **two** cancer waiting time performance targets<sup>82,83</sup>;
- The Republic of Ireland has a number of key performance indicators.<sup>84</sup>

Unfortunately, performance cannot be readily compared with that of other jurisdictions given the way the targets are set and measured.

## 8.2 Northern Ireland - Ministerial cancer waiting time targets

Three Ministerial cancer waiting time targets were introduced in Northern Ireland in 2009. They have remained unchanged ever since. The Department of Health publishes quarterly data on how the health and social care Trusts have performed against the targets.<sup>85</sup> Ministerial targets for 2016/17 are shown in Table 4, however these have some limitations; for example, they do not assess the total patient waiting time from referral to treatment, and the last target **only** applies to breast cancer.

Table 4. Cancer waiting time targets

Cancer waiting time targets (Northern Ireland)
<p><b>62 Day Ministerial Target</b></p> <p>At least 95% of patients should begin their <b>first treatment</b> for cancer within 62 days following an urgent GP referral (red flag) for suspect cancer.</p>
<p><b>31 Day Ministerial Target</b></p> <p>At least 98% of patients <b>diagnosed</b> with cancer should receive their first definitive treatment within 31 days of a decision to treat.</p>
<p><b>14 Day Ministerial Target</b></p> <p>All urgent <b>breast cancer</b> referrals should be seen within 14 days.</p>

<sup>80</sup> Health and Social Care (Commissioning Plan) Direction (Northern Ireland) 2016.

<sup>81</sup> NHS England Website. National Cancer Waiting Times Monitoring Data Set Overview. Available online at: [http://www.datadictionary.nhs.uk/data\\_dictionary/messages/clinical\\_data\\_sets/data\\_sets/national\\_cancer\\_waiting\\_times\\_monitoring\\_data\\_set\\_fr.asp](http://www.datadictionary.nhs.uk/data_dictionary/messages/clinical_data_sets/data_sets/national_cancer_waiting_times_monitoring_data_set_fr.asp) Website accessed 5.5.17

<sup>82</sup> ISD Scotland. Cancer waiting times. Available online at: <http://www.isdscotland.org/Health-Topics/Waiting-Times/Cancer/> Website accessed 5.5.17

<sup>83</sup> NHS Wales Cancer Waiting Times Quality Report. Available online at: <http://gov.wales/statistics-and-research/nhs-cancer-waiting-times/quality-report/?lang=en>

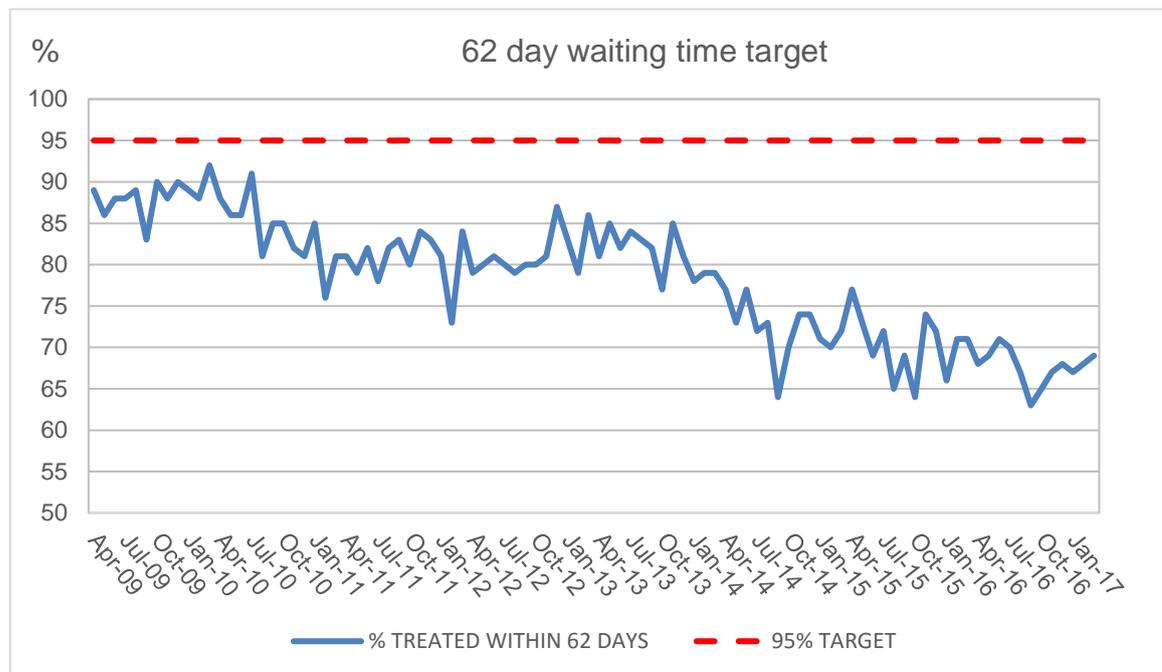
<sup>84</sup> <http://www.hse.ie/eng/services/list/5/cancer/pubs/intelligence/kpis.html>

<sup>85</sup> See Department of Health Website. Cancer waiting times. Available online at: <https://www.health-ni.gov.uk/articles/cancer-waiting-times> Website accessed 7.5.17

The following graphs show the overall performance of all HSC Trusts combined (at a Northern Ireland level) against the three waiting time targets between April 2009 and January 2017.

### 62 Day Cancer Target (95% of patients get first treatment in 62 days)<sup>86</sup>

Figure 7. All Trusts performance: percentage of patients treated in 62 days



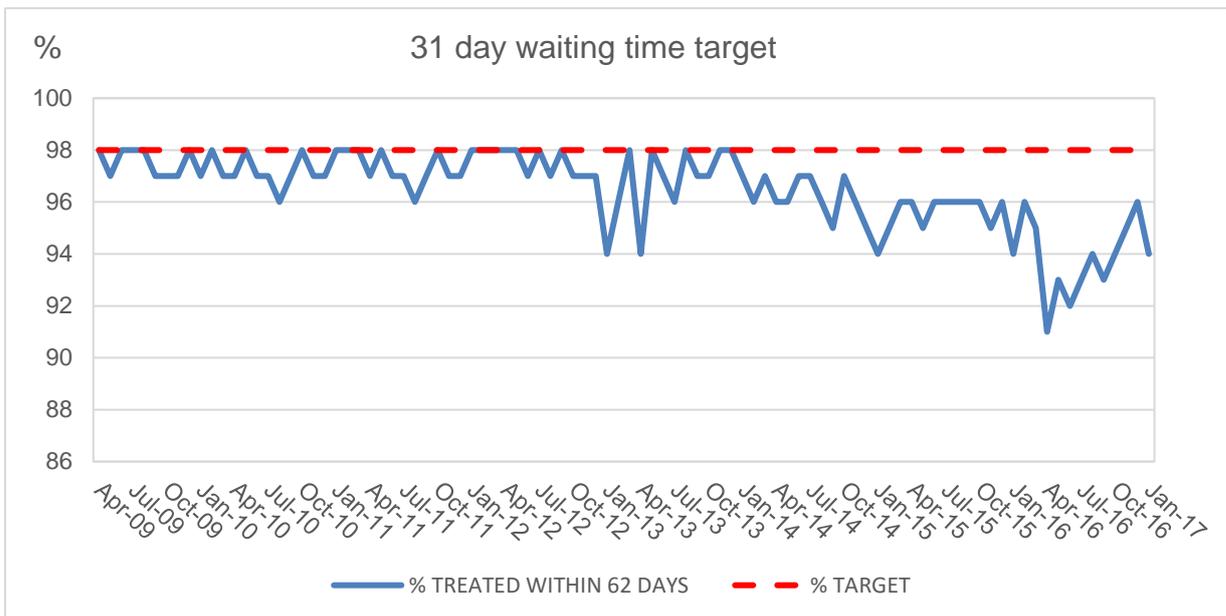
All HSC Trusts have a target that 95% of patients should begin their first treatment for cancer within 62 days following an urgent GP referral (red flag) where cancer is suspected. In Figure 7, the overall performance of HSC Trusts across Northern Ireland is shown in the blue line against the 95% target (red line).

- As can be seen, between 2009-2017 the 62-day target **has not been reached on a Northern Ireland level since its introduction 8 years ago.**
- In fact, performance has severely deteriorated in recent years. This suggests patients are currently experiencing severe delays in getting a cancer diagnosis.
- Data was requested from the Department of Health regarding the number of people waiting over 3, 5, and 8 months for their first cancer treatment. Information was also sought regarding which cancers had the longest waits. This information was not received.

<sup>86</sup> Raw data provided by Capps via Department of Health (Northern Ireland), Hospital Information Branch 21.6.17

**31 Day Cancer Target (98% of patients diagnosed receive first treatment in 31 days)<sup>87</sup>**

Figure 8. All Trusts performance: percentage of patients treated in 31 days



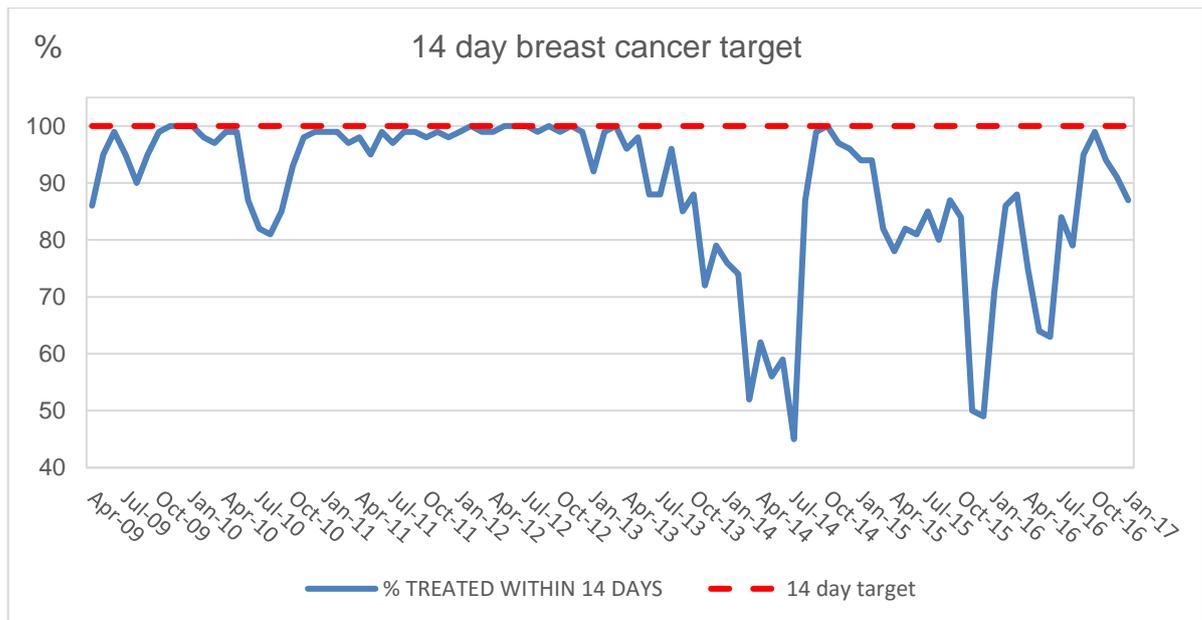
- This target applies to patients who have a diagnosis of cancer.
- It has not been met on a Northern Ireland level since December 2013.
- This suggests people are waiting longer than recommended before their treatment starts.

**14 Day Cancer Target (breast cancer only- urgent referrals seen in 14 days)<sup>88</sup>**

Figure 9. All Trusts performance: percentage of breast cancer patients seen in 14 days

<sup>87</sup> Raw data provided by Capps via Department of Health (Northern Ireland), Hospital Information Branch 21.6.17

<sup>88</sup> Raw data provided by Department of Health (Northern Ireland) Source: Departmental Return SDR2, Hospital Information Branch 21.6.17



- The 14-day breast cancer target is not being met.
- The target was last met in October 2014. This was however, short-lived, as performance varied greatly between then and 2016 - when performance improved to near target level (99% in October 2016). Since October 2016, the target has started to deteriorate again.

Overall, all three Ministerial cancer waiting time targets have not been met.

Information was also sought from the Department of Health about what actions are being taken to improve waiting time performance, but a response was not given.

It remains unknown what impact such delays are having on patients, but there are likely to be some negative implications regarding outcomes. It also begs questions relating to why the targets have not been met for several years, why are more manageable targets not being set, and what actions are being taken to reduce deteriorating waiting times? Given also that demand for cancer services are rising and will continue to increase – largely due to the aging population, this presents a worrying picture for the future.

## 9. Conclusion

Whilst significant advances have been made in cancer care and treatment, there remain variations in provision and many gaps still exist. Policy documents lack evaluation and follow-up action. Furthermore, Northern Ireland is the only jurisdiction in the UK and Republic of Ireland not to have updated its cancer strategy. Evidence also suggests more could be done in terms of earlier diagnosis and more timely treatment. Some of the key challenges linked to this include: workforce and resource issues in primary and secondary care, educating people - where possible, about the signs and symptoms of cancer, and poor Ministerial waiting time target performance.