Transforming cancer outcomes in Northern Ireland

Cancer Research UK recommendations for the cancer strategy in Northern Ireland

Summary

Cancer Research UK (CRUK) is the world's largest independent cancer charity dedicated to saving lives through research. We support research into all aspects of cancer which is achieved through the work of over 4,000 scientists, doctors and nurses. In 2018/19, we committed £546 million to fund and facilitate research in institutes, hospitals and universities across the UK. We are also the largest charity funder of cancer research in Northern Ireland. CRUK wants to accelerate progress so that 3 in 4 people survive their cancer for 10 years or more by 2034.

In 2017, 9,521 people were diagnosed with cancer in Northern Ireland – 26 people every day[i]. By 2030, it is expected there will be over 12,000 cancer diagnoses a year, partly as a result of a growing and aging population. Although survival has improved in Northern Ireland over the last fifty years, it is still poorer than in other comparable countries.[ii, iii] In Northern Ireland issues with the organisation and capacity of diagnostic services meant that between April and June 2019, just 54% of patients received their first treatment within 62 days of an urgent referral for cancer. The 62-day Ministerial Target of 95% has never been met[iv].

Given the significant challenges facing cancer services in Northern Ireland, **Cancer Research UK strongly welcomes the current development of a cancer strategy for Northern Ireland being led by the Department of Health.** Over the past 10 years several frameworks, strategies and plans for cancer services have been published in Northern Ireland. However, none of these have been completely comprehensive and all are now out of date. It is imperative the mistakes of the past are learned from, and a new and ambitious cancer strategy is developed that offers a vision for transforming cancer outcomes for cancer patients in Northern Ireland.

In particular, we must see:

- **Clear, measurable targets over the first five-year period with ongoing review of progress against ambitions including an interim review after two years**
- **A commitment to a full review and refresh of the Strategy halfway through the 10 year lifespan of the Strategy, ensuring the Strategy is updated following assessment to guarantee it remains relevant and impactful to 2030**
- **Appropriate leadership and sufficient and sustainable funding to achieve much needed transformational change in cancer services**

Building on the call for evidence-led transformation in *Systems, Not Structures: Changing Health & Social Care*[v], a cancer strategy could act as a vehicle for wider reform of the health and social care system in Northern Ireland. A new cancer strategy could support in delivering transformation to areas such as prevention, diagnostic and treatment services which would benefit a range of conditions.

The return of devolved government to Stormont is an invaluable opportunity to seize the initiative and develop, adopt and implement an ambitious cancer strategy that will deliver improved outcomes for cancer patients in Northern Ireland. Development of a cancer strategy has support from all parties represented in the Northern Ireland Assembly, reflecting consensus across the political spectrum and demonstrating the clear imperative to drive forward transformation in cancer services. This consensus should guarantee sufficient investment to deliver an ambitious cancer strategy that delivers transformation in cancer services and builds capacity as cancer incidence rises.

While the overall ambitions of the Strategy must be aspirational and seek to deliver ambitious transformation of cancer services, actions that are both impactful and achievable in the light of present financial constraints and the current pressures on the health system are also vitally important. This paper seeks to identify both short term action and longer-term ambitions. Following the current process of developing recommendations for the DoH to consider, an inclusive and transparent process of prioritisation should be undertaken. This process should identify what can be delivered and see improvements in outcomes and experience for cancer patients in the short term, and which ambitions will require longer for implementation.

Cancer Research UK looks forward to working closely with the Northern Ireland Department of Health to explore the priorities for transforming cancer services. There are opportunities right across the cancer pathway to drive improvements in outcomes, and we have identified the areas of most potential in:

- A radical shift to prevention
- Efforts to diagnose cancers earlier and reduce late stage diagnosis
- Ensuring equitable access to the highest quality appropriate treatments
- Creating a cancer workforce prepared for a future of increasing cancer incidence
- Optimising cancer data and informatics to improve services and patient outcomes
- Fostering a strong culture of research in the health service

Underpinning the strategy should be a bold vision to transform cancer outcomes in Northern Ireland, with clear and measurable ambitions to **address modifiable cancer risk factors, reduce late stage diagnosis and diagnose more cancers at an earlier stage, improve access to effective and evidence based treatments and improve survival.**

Below we have set out the 14 clear commitments we believe should be prioritised in a new cancer strategy to unlock the benefits of the greatest opportunities to transform cancer services and accelerate progress in improving cancer outcomes.

Public health and prevention

1. **Clear population-level actions on the prevention of modifiable cancer risk factors such as smoking, obesity, and alcohol, including developing a new strategy to reduce alcohol consumption**
2. **Share in CRUK’s vision, and set a target for a smoking prevalence of less than 5% by 2035 – this target should then be delivered though action with a focus on provision of stop smoking services and tobacco control public health campaigns**

Early diagnosis

3. **Full implementation and optimisation of the Faecal Immunochemical Test (FIT) for bowel screening no later than 2023, with clear and transparent timelines for set out by the Public Health Agency to achieve this**
4. **Introduction of the HPV test as the primary test for cervical screening no later than 2023, with clear and transparent timelines for set out by the Public Health Agency to achieve this**
5. **Commission an audit of diagnostic capacity and how diagnostic services can be optimally organised, to inform a centralised initiative to introduce NICE NG12 referral guidelines or updated guidance**

Access to treatments

6. **Ensure the swift adoption of innovative treatments that have been shown to be effective**
7. **Conduct a review of equitability of access to the best evidence-based treatments, and improve the quality of cancer treatment data to allow ongoing monitoring**

Workforce

8. **Review the cancer workforce with a focus on diagnostic professions to identify the extent and impact of shortages, followed by a fully funded plan to address gaps in the short term and ensure there are enough staff to meet need in the future**
9. **Develop and support skills mix approaches to ensure that workforce is deployed as efficiently as possible**

Cancer Data

10. **Develop a comprehensive strategy for cancer data and informatics, including the full implementation of the recommendations of the Review of the Northern Ireland Cancer Registry and engagement with all relevant stakeholders, so that cancer data is used to inform and support delivery and transformation of cancer services**
11. **Guarantee that when the Encompass electronic patient record system is introduced it supports transformation in cancer services and is a valuable enabler of research and innovation**
12. **Urgently implement the Health and Social Care (Control of Data Processing) Act (Northern Ireland) 2016 to enable data sharing for medical research, service improvement and direct patient care**

Research

13. **Develop a plan to embed research throughout the health and social care system in Northern Ireland, which establishes research as a core part of the system and fosters a culture of research at all levels**
14. **Aim to increase the number of clinician-patient conversations about taking part in cancer research, including exploring the possibility of establishing a system to signpost ongoing clinical trials to patients**

Improve public health to prevent more cancers

Cancer Research UK recommendations for the new cancer strategy:

Clear population-level actions on the prevention of modifiable cancer risk factors such as smoking, obesity, and alcohol, including developing a new strategy to reduce alcohol consumption

Share in CRUK's vision, and set a target for a smoking prevalence of less than 5% by 2035 – this target should then be delivered though action with a focus on provision of stop smoking services and tobacco control public health campaigns

Nearly 40% of cancers diagnosed in Northern Ireland are attributable to lifestyle and environmental factors.[vi] These factors are modifiable, which means **many of these cancers could be prevented.** Focusing on prevention is vital because as the population ages and grows we need to aim to reduce cancer incidence and maintain sustainability. Interventions to prevent cancer are also likely to be **more cost-effective** than delivering cancer treatments.

Reducing smoking prevalence

Though positive progress has been made in reducing smoking rates, 15.5% of people in Northern Ireland are still currently smokers. This means around 213,000 people are still exposed to the most serious modifiable cancer risk factor today.[vii] The 10-year tobacco control strategy for Northern Ireland, published in 2012, signalled an ambition for a tobacco-free society and set out steps to achieve it.[viii] The mid-term review of the tobacco strategy has experienced several delays and has missed its initial completion target of April 2018. We would like this review to be completed urgently, and when published must reaffirm this commitment and outline action to ensure that tobacco reduction in Northern Ireland remains on course. We recommend that Northern Ireland also uses the review to bring alignment with the **target for a tobacco-free UK** by 2035 – where less than 5% of adults smoke.[ix] The Scottish Government has committed to this target while in England the Department of Health and Social Care has committed to the target but not yet the timetable.

The next Northern Ireland Executive should maintain its commitment to implementation of the tobacco control strategy. This must include sufficient and sustainable funding for **specialist Stop Smoking Services**. Despite offering the most effective way to support people to stop smoking (behavioural support and prescription medication),[x] uptake of these services is declining.[xi] Stop Smoking Services should be promoted, alongside further action to de-normalise smoking and discourage uptake, through **regular and fully funded media campaigns targeted at the most deprived communities**, given that lung cancer is almost twice as common in the most deprived quintile compared to the least.[xii]

Tackling obesity

Obesity is the biggest preventable cause of cancer after smoking,[xiii] and can be attributable to at least 13 cancers.[xiv] The latest figures show that 64% of adults and 26% of children in Northern Ireland are overweight or obese.[xv, xvi]

The next Northern Ireland Executive must achieve the targets established in the Department of Health's 'A Fitter Future for All' framework: a reduction in overweight and obesity of **4% in adults and 3% in children by 2022**.[xvii]

This can be achieved by creating an environment where healthier choices become easier, particularly among more socio-economically deprived groups. This will involve working with other UK and Republic of Ireland public health organisations to reduce children's exposure to junk food marketing, reformulate products high in sugar and calories, and limit the use of price promotions of unhealthy foods.

Alcohol consumption

With the expiration of phase two of the Strategic Direction for Alcohol and Drugs in 2016[xviii], the Northern Ireland Executive must commit to a **strategic direction to reduce alcohol consumption**. This should introduce minimum unit pricing to minimise the harm to those who regularly drink more than 14 units per week. For all appropriate areas in obesity and alcohol, Northern Ireland should explore opportunities to work with the Republic of Ireland to deliver most impact through an 'island-wide' approach.

UV exposure and HPV Vaccination

We support the continued implementation, monitoring and evaluation of the **Skin Cancer Prevention Strategy and Action Plan**.[xix] This sets out methods to reduce excess UV exposure leading to skin melanoma, making clear the importance of prevention to address the increasing rates of skin cancer in Northern Ireland.

There is a clear link between human papillomavirus (HPV) and a number of cancers, particularly cervical cancer. Since 2008, 12- and 13-year-old girls in Northern Ireland have been routinely offered **the HPV vaccine**. Uptake is high, but figures in 2014-15 were lower both for the 3-dose and 2-dose programmes.[xx] The Public Health Agency (PHA) must work to ensure pockets of low uptake are addressed, while recognising that taking part is an individual choice. The extension of the vaccine's availability to men and boys aged 15-45 who have sex with men is welcome – PHA should monitor its uptake and ensure that it is well publicised. The commitment of the DoH to implement the recommendation of the Joint Vaccination and Immunisation Committee, to deliver HPV vaccination to adolescent boys, is highly welcome. Following implementation, the DoH should monitor uptake across all demographics and implement evidence-based interventions to address and improve informed uptake.

Driving forwards early diagnosis

Cancer Research UK recommendations for the new cancer strategy:

Full implementation and optimisation of the Faecal Immunochemical Test (FIT) for bowel screening by 2023, with clear and transparent timelines set out by the Public Health Agency to achieve this

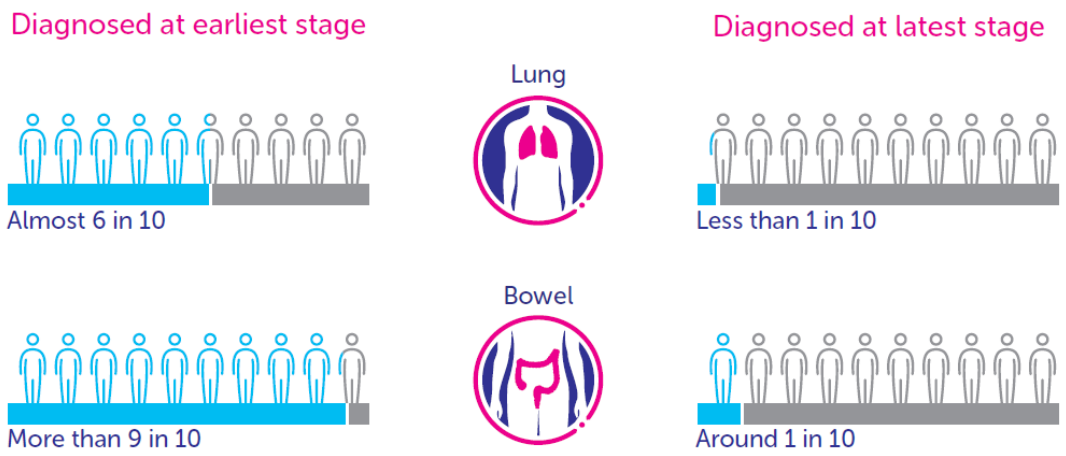
Introduction of the HPV test as the primary test for cervical screening by 2025, with clear and transparent timelines set out by the Public Health Agency to achieve this

Commission an audit of diagnostic capacity and how diagnostic services can be optimally organised, to inform a centralised initiative to introduce NICE NG12 referral guidelines or updated guidance

For cancer survival in Northern Ireland to improve, it is essential that cancers are **diagnosed at an earlier stage** when treatment is more likely to be successful. When cancer is diagnosed earlier, patients have a significantly higher chance of survival. Research conducted in England shows that, for the eight most common cancers, around **80 per cent of patients survive for ten years or more when diagnosed at an early stage (one or two)**. When diagnosed at a late stage (three or four), the figure drops to 25 per cent.[xxi] Treatment costs can also be significantly lower when cancer is diagnosed earlier.[xxii]

However, Northern Ireland sees 45% of cancer patients diagnosed at a late stage, showing that it is vitally important to **increase efforts to diagnose cancers earlier**[xxiii]. Research by the International Cancer Benchmarking Partnership, a programme led by Cancer Research UK, has shown that some patients in Northern Ireland experience longer interval lengths from symptom presentation to start of treatment compared to other similar countries. For colorectal and lung cancers, the patient and diagnostic intervals in Northern Ireland are among the longest.[xxiv] As well as this, 20% of patients in

Five-year survival by stage at diagnosis



Earliest stage = stage 1; latest stage = stage 4.
Data is age-standardised net survival for adults (aged 15 to 99 years) in England in 2012-2016 followed up to 2017.
Source: Cancer survival in England, ONS/PHE, 2019.

Northern Ireland are diagnosed in an emergency, which is the same as the figure in England over the same period and where reducing emergency presentations is a key priority[xxv].

Cancer Research UK supports the emphasis placed on early diagnosis of cancer in the Service Framework, and in recent commissioning plans. Recent evidence has also shown that only 28% of patients diagnosed with cancer in Northern Ireland are diagnosed following a red-flag referral, which is less than 35% diagnosed via an urgent referral in England[xxvi]. A centralised initiative by the NI DoH should coordinate transformation within diagnostic services to support NG12 implementation, including GP direct access to appropriate diagnostic tests and the development of multi-disciplinary diagnostic centres.

Diagnostic capacity & organisation of diagnostic services

Ensuring that there is **sufficient capacity in diagnostic services** is vital to improving early diagnosis. Diagnosing more cancers at an early stage will require more patients to be referred for diagnostic tests at a lower threshold of risk, while rising incidence of cancer will mean increasing demand for diagnostic tests if these cancers are to be diagnosed at an early stage.

Cancer Waiting Times (CWTs) provide a useful barometer of system pressure and performance of cancer services, and set clear expectations on the health and care service to deliver timely diagnosis and treatment to cancer patients. In Northern Ireland, performance against the whole suite of CWTs is unacceptably poor and indicates a significant and consistent lack of capacity in diagnostic services. Northern Ireland has never met the 62-day urgent referral to first definitive treatment target, and performance has continually deteriorated since its introduction. Between July and September 2019, just 52.5% of those urgently referred and subsequently diagnosed with cancer received treatment within 62 days – meaning 529 people with cancer did not.[xxvii]

CWTs are process measures rather than outcome measures, so achieving the standards does not necessarily improve survival or stage at diagnosis. To truly drive transformation in cancer services it is important that CWTs sit within a suite of quality and outcome measures. They also do not reveal the entire scale of the problem – we have heard anecdotal evidence that waits for cancer patients who are not urgently referred can be significantly longer than those faced by those captured by CWT metrics. Indeed, the second quarter of 2019/20 saw over half (56.9%; 79,842) of all patients waiting longer than 9 weeks and 30.3% (42,546) of patients waiting longer than 26 weeks for a diagnostic test.[xxviii] Not all of these patients will be waiting for a test to confirm or rule out a diagnosis of cancer, but the figures clearly demonstrate a **lack of capacity in diagnostic services** that is negatively impacting not just cancer patients but all patients accessing diagnostic services.

Evidence from England has shown that overall CWTs have been successful in reducing the time from referral to treatment since their first introduction in 1999, demonstrating their potential value in driving improvements in cancer services. Moreover, waiting for a cancer diagnosis, or to have cancer ruled out, and treatment is an anxious time for patients and their families, and efforts to reduce this time are important to patients' experience of care. **Significant investment will be required to create the capacity needed to reverse the downward trend in cancer waiting time performance, and deliver timely diagnosis and treatment.**

To understand the workforce, kit and infrastructure implications of this, Northern Ireland should review current diagnostic capacity and determine what actions are needed in the short-term to address any gaps. This review should take into account workforce, infrastructure and kit, and oversight and management, and contribute to ensuring that the health system can deliver on important early diagnosis initiatives such as the introduction of new guidance for cancer recognition and referral, and optimisation of screening interventions.

Pressures on the diagnostic workforce are a key contributor to missed targets and are discussed in more detail in a later section of this paper. Organising diagnostic services more efficiently could also contribute to faster diagnosis and releasing more capacity. Until now, imaging services have been locally run rather than centrally organised. This has been acknowledged by the Health and Social Care Board as contributing to variation.[xxix] Though not all Trusts carry out all diagnostic tests, waiting time figures still indicate significant variation. Between July and September 2019, 62.0% of patients waited longer than 9 weeks for a diagnostic test in the Belfast HSC Trust, compared to 30.7% in the Western HSC Trust.[xxx]

The new cancer strategy for Northern Ireland should build on the recent consultation on the organisation of imaging services to identify how **diagnostic services can be better organised**, including considering how to maximise the skill mix of the workforce. **Alternative pathways and options for diagnosis** should also be explored, by developing one-stop diagnostic services to avoid patients moving back and forth between services if they have non-specific but concerning symptoms. Direct access to some diagnostic tests for GPs could also release some capacity in diagnostic services.

GP direct access to diagnostic tests helps to reduce the steps that patients must go through to reach a diagnosis. It is also particularly important given that general practice in Northern Ireland is under pressure[xxxi]; allowing GPs direct access to tests gives them another option to investigate symptoms in people who they suspect might have cancer. However, direct access to diagnostic tests for GPs is variable by geography.[xxxii] As part of work to better organise diagnostic services, the Department of Health should **conduct a rapid review of direct access to diagnostic tests for GPs** and use any findings to inform future reorganisation of diagnostic services.

Screening

We support the PHA's aim to increase informed uptake for the current **bowel, breast and cervical cancer screening programmes**. It is essential that these efforts continue, and we welcome the current review of bowel and cervical screening programmes[xxxiii].

The UK NSC recommends replacing the Faecal Occult Blood Test (FOBT) with the **Faecal Immunochemical Test (FIT) in bowel cancer screening**. FIT can detect many more cancers and growths which may develop into cancer if left to grow. The test is simpler, only requiring one stool sample; this increases participation, as shown in Scotland where the national roll-out of FIT has seen uptake **increase to 63.9% in 2018 compared to 55.9% in 2016** when for FOBT was still in use. There are also indications that harder to reach groups are more likely to take up FIT screening, with participation increasing from **8.2% to 18.4%** across the period.[xxxiv]

In line with guidance from the NSC we recommend that FIT be introduced at the earliest opportunity, ideally with a high level of sensitivity to fulfil its potential to detect more cancers and precancerous changes. This should be a priority considering the most recent uptake figures show a rate of just 59.4%,[xxxv] alongside the prevalent serious health inequalities in Northern Ireland. After FIT implementation, the bowel screening programme should be offered every two years to men and women aged 50-74. Northern Ireland is now the only nation in the United Kingdom that still has not implemented, or committed to implementing, bowel screening from 50-74. Clear and transparent timelines for the introduction of the FIT test for bowel screening should be outlined by the Public Health Agency, with an ambition to drive uptake to 75%. Introducing FIT at a high level of sensitivity and with an extended age range will require additional capacity in endoscopy services, so it is essential that the new cancer strategy conducts a full review of diagnostic services to ensure that there is sufficient capacity for an optimal bowel screening programme.

We recommend the introduction of the **HPV test as the primary test for cervical screening**, replacing the current liquid-based cytology (LBC). HPV as the primary test is more effective in identifying women who are at risk of cervical cancer and it will save more lives by determining a woman's risk earlier. The test is more reliable, so women may not need to come for screening as often in the future. Once implemented, HPV primary testing will also be less expensive than the current LBC test. Following implementation of the HPV test as the primary test for cervical screening, PHA should work towards risk stratification for cervical cancer screening through extending test intervals to 5 years for women who test HPV negative.

Awareness

Awareness campaigns are important in raising understanding of the key signs and symptoms of a range of cancers. Improving awareness of symptoms encourages people to visit their GP sooner, promoting early diagnosis. Effective awareness campaigns should particularly target those living in deprived areas and should also be run regularly, ideally yearly, to maintain awareness of cancer signs and symptoms.

We are concerned that to date results from an evaluation of the PHA's **'Be Cancer Aware' programme** have yet to be published, over 3 years since the campaign last ran. The programme ran a general media campaign promoting cancer awareness as well as site specific campaigns for breast and lung cancer. It is important that **there is detailed and publicly available evaluation of the impact of awareness campaigns going forward,** on the overall number of referrals and diagnostic test results, and the staging of cancers diagnosed.

There has not been a cancer awareness campaign in Northern Ireland for almost 3 years. The PHA should work towards resuming the Be Cancer Aware campaigns, rotating between site-specific campaigns and targeting hard to reach groups. However, ultimately awareness campaigns can only be successful if there is sufficient diagnostic capacity in the system. Urgent action must be taken to increase diagnostic capacity and ensure that services are organised efficiently so that awareness campaigns are sustainable and an uplift in diagnostic tests does not lead to a deterioration in waiting times.

Improve access to modern treatments

Cancer Research UK recommendations for the new cancer strategy:

Ensure the swift adoption of innovative treatments that have been shown to be effective

Conduct a review of equitability of access to the best evidence-based treatments, and improve the quality of cancer treatment data to allow ongoing monitoring

The growing and ageing population will mean more patients will require access to treatments. This will also mean a greater proportion of patients will have complex needs and multiple health conditions, and therefore may require more support to access treatment. Improving early diagnosis will also have an impact on the cancer treatment landscape, giving more patients curative treatment options, **including increased use of surgery and radiotherapy.** Research will continue to develop new treatments in the future, requiring appropriate mechanisms and concomitant funding to ensure the swift adoption of new evidence-based treatments.

In addition, the landscape of access to innovative new treatments is changing. For example, around 90% of cancer drugs now in late phase development are so-called "precision" medicines, which target specific genetic or molecular variations in patients' cancer cells. Patient access to these drugs is reliant on having the genomic testing infrastructure and capacity in place to determine which individual patients are likely to respond to these targeted medicines. It is important these shifts in treatment options are acknowledged in future service planning as part of the cancer strategy.

Every person diagnosed with cancer across Northern Ireland should be given equitable access to the best, evidence-based treatments for their condition. We welcome recent commitments that have been made to improve access to treatments in Northern Ireland, and it is important that these are implemented in full and made routine practice as part of the strategy. It is also important that actions evolve to cope with growing demand. It will be important to monitor variation in access to new treatments across Northern Ireland and across different groups of patients, and take action to mitigate any unwarranted variation.

Swift Adoption of New Evidence-Based Cancer Treatments

The implementation of reforms to the Individual Funding Request (IFR) process in September 2018 was a welcome development. The new cancer strategy should commit to monitoring patient and clinician engagement with the reformed IFR process, and on the outcomes of that process, ensuring patients can access licensed medicines which have not been appraised or recommended by NICE when appropriate to treat or manage their disease.

Similarly, the Department's decision to make managed access drugs available in England through the Cancer Drugs Fund (CDF)[1] available to patients in Northern Ireland on the same basis as drugs which have been recommended by NICE as suitable for routine commissioning was a positive and crucial step, closing a clear geographical inequality of access to these medicines.

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[1] Note that following the 2019 UK General Election, the Government has signalled the intention to expand the CDF into a £500 million Innovative Drugs Fund, offering a managed access model for all innovative medicines.

However, we are concerned the present funding may not accurately represent the expenditure required to meet patient need for these innovative medicines. The cancer strategy should set out a sustainable long-term approach to the funding and commissioning arrangements for these medicines based on the most up-to-date data, to ensure patients in Northern Ireland can access the best, evidence-based drugs for their cancer. This includes addressing the current discrepancy in which central funding covers the direct cost of novel treatment options such as immunotherapy drugs, but Trusts are expected to cover the secondary costs of care without increased funding.

The different ways in which these drugs are administered to patients (for example, they are often given continuously rather than on cycles), and the differences and uncertainty associated with their side-effect profiles compared to conventional chemotherapy, will have significant implications for the cancer workforce and treatment services. The cancer strategy should set out how local service providers will be supported to develop the required capacity to safely deliver these new drugs, including relevant education for healthcare professionals.

We welcome the significant investment that was made to establish the radiotherapy centre Altnagelvin Area Hospital. Looking forwards, the strategy should maintain efforts to ensure appropriate access to advanced radiotherapy – such as brachytherapy, intensity modulated radiotherapy (IMRT) and stereotactic ablative radiotherapy (SABR), for all those patients who would benefit. This must also consider the impact on the radiotherapy workforce, since as well as overall cancer incidence increasing, some modern radiotherapy can take longer to plan.

Additionally, around 90% of new medicines emerging from the R&D pipeline are genetically targeted medicines.[xxxvi] These can be more effective and less toxic than existing treatment options, but they also require patients to undergo genomic testing to determine their eligibility for the treatment. As more targeted therapies emerge from the pipeline, targeting a wider range of genetic variations found in some patients' cancers, this will place additional pressure on existing molecular pathology systems.

Consistent and equitable access to beneficial genomic tests across Northern Ireland is critical to ensure the Health Service can effectively identify patients who could benefit from these new targeted therapies, ensuring the system is efficiently directing patients towards targeted medicines recommended for routine funding.

Equity of Access

As we highlighted in our 2016 report, a lack of publicly available data means that **the current picture of access to treatment is difficult to assess[xxxvii].** Little progress has been made since its publication. For example, there is a recommendation by the Radiotherapy Board for around 50% of patients to have access to modern radiotherapy techniques such as intensity modulated radiotherapy[xxxviii]. However, we do not know how close Northern Ireland is to this target, or the extent of variation, because there is no publicly available data.

The Strategy must commit to establishing data infrastructure that can accurately collect and publicly release robust data on treatment delivery and outcomes in Northern Ireland. The strategy should also ensure resource is made available for regular analysis of data from the Regional Information

System for Oncology and Haematology (RISOH), to monitor equitability and speed of uptake of new medicines, and explore unwarranted variation in access to the best evidence-based treatments.

To ensure greater equitability of access, consistency of best practice in decision-making is key. Multidisciplinary teams (MDTs), considered the gold standard for cancer patient management[xxxix], bring continuity of care and reduce variation in access to treatment – ultimately improving outcomes for patients. The number of patients discussed in MDT meetings has grown significantly, as has the complexity of patients, due to an ageing population and the growing number of treatment options available. However, the way that MDT meetings are organised has not adapted to cope with this increased demand, meaning individual patient's treatment is discussed much more briefly. Consequently, MDTs often do not include information such as patient preferences, comorbidities or whether the patient is suitable for a clinical trial.

The Strategy for Northern Ireland offers a timely opportunity to **review MDTs and consider new ways of working**. In our 2017 report, we recommend streamlining MDT meetings, and improving the quality of discussions[xl]. This would be particularly beneficial for more complex patients, who would benefit the most from the input of the full MDT, and could lead to more efficient usage of oncology staff time. We welcome that NICaN has already taken steps to improve MDTs as a result of our report, and this work should be supported on an ongoing basis.

There must also be a **concerted effort to address inequalities in access to treatments**, particularly for older patients, who are more likely to have complex needs and multiple health conditions. The population of Northern Ireland aged 75 and over is forecast to rise from 131,696 in 2016 to 217,251 in 2034, a 65% increase[xli]. Across the UK, 36% of all cancer cases are diagnosed in people aged 75 or over, and by 2035, this group is projected to account for 46% of all cancer diagnoses and 62% of all cancer deaths[xlii].

There is a significant body of evidence from across the UK that indicates there are barriers to accessing modern, evidence-based treatments for older patients. A report by the National Cancer Intelligence Network (NCIN) and CRUK found that across 20 cancer sites, older patients were less likely to have major surgical resections[xliii]. It has also been reported that the use of chemotherapy declines with age, in several types of cancer[xliv].

Whilst some of the variation in access to treatment can be accounted for by patients choosing not to pursue active treatment, there may also be some who are simply not being offered curative treatment that could benefit them, because assumptions have been made about their fitness based on their age. In contrast, we also heard anecdotally that some feel pressured by their clinicians to undergo intensive curative treatment.

One reason for this issue is that there are not adequate ways to properly assess the needs of older patients with complex needs. To get this balance right, **treatment decisions must consistently be personalised around each individual's situation.** To achieve this, there must be wider use of geriatric assessment tools across the health service. Reforms to increase the consistency of MDT decision-making would also benefit older patients with complex needs.

A major barrier to accessing treatment older patients face is long travel times, which is particularly important where older patients live in a rural area. 37% of the population of Northern Ireland live in rural communities[xlv], and rural communities in the UK tend to be older than the urban population[xlvi]. Research by CRUK found that clinicians based at sites where patients are more likely to have to travel for treatment – such as tertiary centres serving a mostly rural area – expressed concerns that older patients could be excluded from treatment, or from taking part in clinical trials. We support the work of the Oncology Services Transformation Programme Board in supporting patients to access treatment closer to home when possible, and hope to see this built on in future and given sustainable funding. When future services are being planned and their performance monitored, **there must be a recognition that older patients are more likely to require additional support to travel to treatment**.

Develop a cancer workforce prepared for the future

Cancer Research UK recommendations for the new cancer strategy:

Review the cancer workforce with a focus on diagnostic professions to identify the extent and impact of shortages, followed by a fully funded plan to address gaps in the short term and ensure there are enough staff to meet need in the future

Develop and support skills mix approached to ensure that workforce is deployed as efficiently as possible

Between March 2017 and September 2019, the number of whole time equivalent (WTE) vacancies in the Northern Ireland Health and Social Care workforce grew from 3,890 WTE places (7.2% of the total current workforce) to 7,203 WTE (12.2% of the total current workforce). These vacancies are prevalent in disciplines crucial to the delivery of care, with 2,269 WTE registered nurse vacancies and 109 WTE consultant vacancies in September 2019[xlvii]. These vacancy rates are not for cancer specifically, but they are a useful proxy to demonstrate workforce shortages. For cancer services, the impacts of staff shortages are only set to become more severe as increasing numbers of people in Northern Ireland are diagnosed with cancer, and as treatments become more complex.

Poor performance against cancer waiting time targets indicates that these workforce pressures are most acute in the **diagnostic workforce**, causing delays in the pathway that undermine efforts to diagnose cancer sooner. The clearest indication of a lack of diagnostic capacity is poor performance against the 62-day cancer waiting time standard. Between April and June 2019, just 54% of patients received their first treatment within 62 days of an urgent GP referral, against a target of 95%[xlviii]. In the same quarter, 93.1% of patients received their first definitive treatment within 31 days of the decision to treat following diagnosis. Though the 98% standard was missed, performance was significantly better than against the 62-day standard, highlighting that the greatest pressures are earlier in the pathway in diagnostic services.

Data collected by CRUK shows that these pressures exist across a wide range of diagnostic professions. CRUK has been highlighting shortages in the **endoscopy workforce**, given the importance of endoscopy to delivering bowel cancer screening programmes and diagnosing colorectal cancers earlier. Across Northern Ireland, there is a **29.4% vacancy rate in nurse endoscopists.** Furthermore, **82% of consultant gastroenterologists are over 50**, meaning consultants reaching retirement could significantly impact service capacity**[xlix].** In radiology, **22% of consultant radiology posts are also currently vacant**, more than 10% higher than any other UK nation[l]. As well as delaying timely diagnosis, these current vacancy rates are also putting significant financial pressure on the health and care system, due to the need to outsource diagnostic activity. **Radiology department outsourcing/insourcing estimated expenditure was £9.25m in 2018**, an increase of £1.5 million from 2017.[li]

These figures have been informed by an informal audit conducted by CRUK, based on an extensive data gathering exercise and engagement with professional networks. However, more work is required to fully understand what shortages exist in the cancer workforce and plan how to address them both in the short term, and to meet patient demand into the future. To address these growing pressures on diagnostic services, the NI DoH should r**eview the diagnostic workforce to identify the extent and impact of shortages, followed by a fully funded plan to address gaps identified in the short term, and ensures there are enough staff to meet need in the future.**

This should:

- Capture a baseline of diagnostic activity and a clear picture of staff numbers to allow an estimate of the current gap between patient need and the supply of staff to be made
- Be based on growing future need of patients, not affordability or vacancy figures
- Take a long-term approach to workforce planning, including projections for how the service will change
- Consider how to collect better workforce data to improve future planning

To make best use of the current workforce, the DoH should also work to ensure that there is **greater use of skills mix in the Northern Ireland HSC workforce**, so that current staff are working to the top of their clinical licenses. There are a number of measures that could support this, including:

- **Centrally driven skills-mix approaches:** Skills-mix approaches are the backbone of modern diagnostic services and there are excellent examples across Northern Ireland of this being embedded. However, there needs to be a demand-driven central approach to upskilling AHPs, increasing the numbers of groups such as advanced practitioner radiographers, nurse endoscopists and Biomedical Scientists trained to dissect tissue and report on some samples
- **Review numbers of training places and consider new ways of training:** New training models can help to embed skills-mix approaches, ensuring the workforce of tomorrow is modern, flexible and lean. Training radiologists and reporting radiographers together may be one of these ways
- **Opportunities in Northern Ireland for advance practice training:** While existing staff shortages make this difficult, recurrent money should be made available to establish advanced training programmes in Northern Ireland, rather than having to send staff elsewhere. This could increase the numbers of Allied Health Professionals training to be at the top of their clinical licence

To allow the current workforce to upskill and enable a skills mix approach, there will need to be extra funding and capacity created to allow staff to undergo training and backfill their roles whilst they are doing so.

The current Oncology Service Transformation project run by the Department has outlined the need to shift the service to one which is clinically led, but medically delivered, and away from the current model of primary delivery by oncology clinical staff. New pathways have been developed for delivery of both chemotherapy and radiotherapy, highlighting the need for a better skill mix in the delivery of treatments which will free consultant time for additional and more complex cases. This approach should be supported with funding for these workforce changes.

Realise Northern Ireland's potential to lead the way in cancer data

Cancer Research UK recommendations for the new cancer strategy:

Fully implement the recommendations of the Review of the Northern Ireland Cancer Registry, to ensure that cancer data is used to inform the delivery and transformation of cancer services

Guarantee that when the Encompass electronic patient record system is introduced it supports transformation in delivers for cancer services and is a valuable enabler of research and innovation

Urgently implement the Health and Social Care (Control of Data Processing) Act (Northern Ireland) 2016 to enable data sharing for medical research

The Northern Ireland Cancer Registry produces very high-quality data. Given its small population size and the relative coherence of its health service, Northern Ireland has the potential to lead the way in cancer data, using data to transform services and overall outcomes for patients. However, change is necessary if this ambition is to be realised. **The recommendations of the recently conducted independent review of the Cancer Registry commissioned by the PHA**[lii] **should be implemented in full** to ensure Northern Ireland is better equipped to make improvements in cancer data in the long term.

Firstly, more comprehensive and robust data must be collected. Gaps in data at specific parts of the cancer pathway need to be addressed, to ensure evidence-based improvement, research and innovation. CRUK has previously recommended that Northern Ireland should develop national datasets for **chemotherapy and radiotherapy activity**[liii]. Developing national datasets for treatment activity should be the priority. The development of the new Regional Information System for Oncology and Haematology (RISOH) should help in this regard.

It will also be important that this data is captured in the Encompass electronic patient record (EPR) system as soon as is possible after the EPR system's introduction, to ensure that clinicians have the fullest understanding of a patient's journey through the cancer pathway. More broadly, the Encompass has significant and positive potential to support improving care and guiding cancer service transformation if optimally deployed. As we approach implementation in coming years, efforts should be made to ensure that the Encompass system:

- Inform an evidence base for cancer-based population health interventions, so that the NHS can more accurately target the communities with the most need
- Can provide a rich source of data for researchers
- Enables patients to view data that has been collected about them, with the longer-term ambition of patients being able to contribute data for their own care
- Make efforts to ensure there is interoperability with NHS England Local Health and Care Record systems and similar national data sharing projects so that patients in Northern Ireland can access care easily across England, and support greater understanding of health systems across the UK

We would welcome more data being made publicly available – in particular, data on treatment uptake and outcomes (covering systemic therapies such as chemotherapy and immunotherapy, as well as radiotherapy and surgery), and timely indicators such as 30-day mortality should be collected and published.

While treatments data should be the priority, a Northern Ireland cancer strategy should include the collection of more high-quality data across the pathway. The Department of Health, Northern Ireland Cancer Registry and the Public Health Agency should work collaboratively and strategically to produce more indicators across the whole cancer pathway. Cancer Research UK is currently developing a UK minimum cancer dataset to support performance measurement, which should be seen as a positive starting point for Northern Ireland to work towards and then build on across the period of the strategy. Consulting with the users of data such as clinicians and researchers, and data processors in disease registries and informatics services will be vital in understanding which data would be most valuable to collect, and which data either do not have significant value or is duplicating work where other data offers the same insight.

The Cancer Patient Experience Survey (CPES) offers a vital insight into the experience of treatment in Northern Ireland's cancer services. We were pleased that the CPES 2018 was accompanied by an action plan. However, there was over three years between the publication of NI CPES 2018 and the last time this survey was conducted. Moving forwards, **CPES should be conducted regularly, with a commitment to develop an action plan to follow up on issues identified**, to ensure that patient experience is at the heart of any service transformation.

Crucial to any efforts to improve data collection and analysis will be ensuring there is sufficient capacity in data informatics across the health system. There are not enough people with analytical and informatics skills across the health service and without this, efforts to extract the most benefit from high quality cancer data will be significantly hindered. Guaranteeing the infrastructure is in place to support the collection, analysis and safe storage of data is also key, and assessing this in light of the introduction of the Encompass system will be important.

We recommend that the PHA moves away from project-based short-term grants and towards **multi-year funding for the Cancer Registry**, allowing for to a more strategic, longer-term approach. The legislative framework must also be equipped to do this, with implementation of the *Health and Social Care (Control of Data Processing) Act (Northern Ireland) 2016* being a crucial next step. Despite receiving Royal Assent in 2016, the resulting regulations still have not been drafted or agreed. It is important that progress drafting these regulations is made, so that the Northern Ireland Assembly can approve these as a matter of urgency. CRUK outlined these issues to the Secretary of State for Northern Ireland in January 2019 and enquired as to whether any progress could be made in lieu of a sitting Assembly.

The use of the powers provided in this Act would enable far greater cooperation across the NI health service, for instance by sharing capacity and support in extremely hard-pressed diagnostic services. They would also allow clinicians and researchers to monitor the impacts of treatments on patients – helping minimise challenging side effects and maximising benefits. Furthermore, this legislation would allow Northern Ireland to integrate cancer data with other UK nations and further afield, which is another recommendation of the Registry review and would offer the potential for valuable comparative analysis. For example, the lung cancer audit already covers England, Scotland, Wales and Guernsey, and these regulations would allow Northern Ireland to take part. The continued delay is a fundamental block to crucial service transformation necessary to ensure the optimal service for patients in NI, and risks falling short of patients’ expectations.

Embed a culture of research and innovation throughout the Northern Ireland health and social care system

Cancer Research UK recommendations for the new cancer strategy:

Develop a plan to embed research throughout the health and social care system in Northern Ireland, which establishes research as a core part of the system and fosters a culture of research at all levels

Aim to increase the number of clinician-patient conversations about taking part in cancer research, including exploring the possibility of establishing a system to signpost ongoing clinical trials to patients

Research is pivotal to developing our understanding of preventing, managing and curing cancer. It should therefore be a key focus of the new cancer strategy – underlying progress in all key areas for our stated commitments is an **active and vibrant research culture**. Evidence suggests that clinical research activity is a driver for high quality cancer care, with better outcomes for patients who are treated in research-intensive hospitals.[liv]

Last year, Cancer Research UK published Bench to Bedside[lv], which outlined a set of policy priorities for the medical research environment in Northern Ireland. The report highlighted concerns about the opportunities for patients to participate in clinical research. The 2018 Northern Ireland Cancer Patient Experience Survey found that research was discussed with **only 15% of patients**, a decline from 18% in 2015[lvi]. There should be a concerted effort to better inform patients about research opportunities reflected in the strategy, including the development of a measurable target for increasing the number of patients having a discussion about clinical research opportunities by the end of the strategy. To work towards achieving this, systems should be put in place to advertise ongoing clinical trials to patients.

The new cancer strategy in Northern Ireland should also consider how to **embed a culture of research at all levels** into the health and social care system. Anecdotal evidence heard by CRUK suggests that many clinicians are not engaged with research, and research and innovation are not ingrained at all levels of the health service. Furthermore, there is currently no mechanism for clinicians in Northern Ireland to protect time to conduct research. Research must be effectively integrated into the health service so that it is as easy as possible for clinicians to engage with research, rather than creating additional pressures. CRUK is currently funding a study to develop policy solutions to improve the capacity of the existing health service workforce to conduct research. This UK-wide study aims to provide insight into action that could be taken in Northern Ireland to integrate research and boost research capacity. These findings will be published in June 2020. DoH should work with representative bodies to create mechanisms for clinicians interested in engaging in research to be able to.

There is also concern about a lack of research representatives at board level in Northern Ireland's Trusts. Individuals involved in, or with experience in, clinical research should be represented at board level to ensure research is at the heart of Trust plans. Due to the small size of Northern Ireland's population, joined up working between Trusts would enable more effective co-ordination of clinical trials in the country. It is vital that research is a core function of everyday healthcare so that we can continue to improve our understanding of cancer and develop better and kinder treatments and preventive measures. It is also vital to maintain links between the departments of Health, Education and Economy to ensure that Northern Ireland continues to be able to support a strong research and health workforce after the UK leaves the European Union.

As well as benefits to the healthcare sector, medical research benefits the wider economy. Each £1 the public invests in cancer research returns around an additional 27p to the UK economy every year. This includes health benefits equivalent to around 10p plus a further 17p, which is the current best estimate of ‘spill over’ effects from research to the wider economy[lvii].

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