Consultation on ‘A Cancer Strategy for Northern Ireland 2021-2031’

Cancer Research UK Response – October 2021

Introduction and summary of recommendations

The publication of this new draft cancer strategy for consultation is a major milestone for cancer services in Northern Ireland. The new strategy will be critical in driving a reduction in preventable cancers, diagnosing cancers earlier, supporting people to live well with and beyond cancer, and ensuring more patients survive their disease. At Cancer Research UK (CRUK), we strongly welcome the draft strategy’s publication and the opportunity to respond through this consultation. In developing our response, we have drawn on our expertise from engaging with, and supporting the development of, this and other cancer strategies across the UK. Our response is informed by extensive intelligence, research and insight, as well as by international best practice. We have also consulted with people affected by cancer in Northern Ireland to ensure their experiences and views are reflected in our consultation response.

The strategy captures the key areas that must be transformed in order to improve cancer outcomes in Northern Ireland, and recognises that these efforts must be underpinned by critical enabling factors – particularly a fully resourced workforce and access to high-quality data. We support this approach, and the ambitious overarching vision for the cancer strategy – equitable and timely service access for all, and the delivery of world class cancer services in Northern Ireland. This ambition will be an important catalyst for change, bringing the cancer services and health system around a shared vision. We recommend the strategy’s overall aims are extended to include a commitment to reducing late stage diagnosis, as this will be key to measuring success. CRUK would be happy to support with the development of a target for reducing late stage diagnoses over the course of the strategy.

There are two important areas that must be addressed in the final strategy which will be critical to ensuring Northern Ireland can effectively make progress towards world class cancer services.

- **Greater detail is needed on the timings and sequencing for delivering the strategy's recommendations,** and interdependencies must be identified to ensure that actions are effectively prioritised and sequenced. In particular, it is essential that the cancer workforce plan, a key focus of the strategy, is fully costed and progresses at pace to enable success. We appreciate that there will be an implementation plan which we hope will address these concerns. CRUK would welcome the opportunity to work with the Northern Ireland Department of Health in developing the forthcoming implementation plan.

- **The Northern Ireland Executive must allocate the necessary funding to fully deliver on the ambitions of this strategy,** without which it will be impossible to deliver the lasting transformation necessary to meaningfully improve cancer outcomes. Cancer patients consulted by CRUK were clear that this is a critical issue, with the aims of the strategy a ‘wish list’ until backed up with funding. Our patient panel also highlighted that world class cancer services felt far off from their lived experience of Northern Ireland’s cancer services, making it especially important that the Executive shows their commitment to this aspiration through committing to the investment required to make it happen. With the upcoming Comprehensive Spending Review in Westminster offering clarity for Northern Ireland’s budget across the crucial initial years of this strategy, the NI Executive must prioritise funding to deliver this strategy and address the chronic issues facing cancer services in Northern Ireland.

The following response outlines CRUK's feedback on the draft strategy. We strongly welcome the direction of travel in the strategy and in each section have indicated our support for particularly important elements. We have also outlined how other areas could be strengthened to ensure they have the greatest impact on improving outcomes. Where appropriate, we have indicated how sequencing and prioritisation will support the effective implementation of the strategy. In the appendix, we outline focussed amendments which would strengthen specific commitments. We would welcome the opportunity to support the further development of the strategy and prioritisation efforts.

Key recommendations:

1. **Fully fund the cancer strategy:** The Northern Ireland Executive must allocate the required funding to deliver the strategy in full in order to deliver on ambitions and see lasting transformation which meaningfully improves patient outcomes.

2. **Address the cancer workforce crisis:** The Cancer Workforce Plan is an essential enabler of the strategy. At the forthcoming Budget, the Northern Ireland Executive must take the opportunity to provide the required funding to ensure that the cancer workforce keeps pace with patient need and can deliver on the transformation to cancer services set out in this strategy.

3. **Improve data collection, quality, and access:** Evidence-based and informed decision making across prevention, early diagnosis and treatment must be underpinned by quality, accessible data. Ensuring sufficient resource, infrastructure and policies are in place for the collection of and efficient access to high-quality data should be treated as a priority for implementing the strategy.

Additional recommendations:

Prevention

- Recommendations on smoking, obesity and skin cancer should be amended to include a requirement to publish and deliver the strategies within a set timeline. The smoking strategy should include the target for NI to reach a smokefree future (adult smoking prevalence of 5% or less across all socioeconomic groups) by 2035.
- Campaigns raising awareness of cancer risk factors and targeting behaviour change must be developed with input from the target audience and funded to run across all mediums, with a targeted focus on specific groups in order to reduce health inequalities.

Early Diagnosis

- The recommendation for raising public awareness of the signs and symptoms of cancer should be extended to include a commitment to encouraging timely help-seeking and improving access to primary care, supporting the strategy's aim of improving early diagnosis rates.
- The strategy should go further and set out timelines for sensitivity and age-range changes to FIT bowel screening. We recommend a review of FIT screening modelling efforts undertaken in the other UK nations when assessing how and when changes to FIT screening are considered.
- The strategy should frame referral and recognition commitments through the overarching principle of ensuring timely recognition and referral for every patient. The core aim of delivering patient-centred care, with the right test delivered at the right time in the right setting, should inform the development of diagnostic hubs.

Treatment

- Quality data, such as clinical audits, must be at the heart of driving change in approaches to cancer treatment. The recommendations in this section do not go far enough to recognise this and overcome existing data challenges – putting in place the required data governance, legislation, infrastructure and funding will be key.
- It is concerning that there are no firm recommendations for radiotherapy included and we urge that this is amended in the final strategy document. In particular, we suggest prioritising recommendations on the rolling replacement of LINACs, and formally committing to a continual cycle of data review and examination.
- Stronger commitments need to be included to enable delivery of the vision set out for clinical trials. Consistent communication with patients and clear targets for improvement are a priority here.

Implementing the Strategy

- It is essential that a robust monitoring and evaluation framework is developed. The strategy commits to reporting at year 3 and subsequent intervals, which must build in opportunities to review progress and adapt the strategy as required, ensuring it remains relevant and impactful to 2031.
- More detail is required on the specific initiatives which will deliver ambitions for data. Multi-year funding for Northern Ireland Cancer Registry should also be secured so that it can plan more strategically and build its capacity accordingly.
- There is no tangible plan to build research capacity – we recommend that the strategy incorporates key recommendations from CRUK's *Bench to Bedside* and *Creating Time for Research* reports in order to increase access to research and accelerate improvements in patient care.

Full response and recommendations

Prevention

We strongly welcome the focus on reducing preventable cancers as a core aim of the strategy. As the strategy recognises, almost 40% of cancers diagnosed in Northern Ireland (NI) could be prevented and are attributable to known modifiable risk factors.[1] Focusing on prevention is critical to reducing cancer incidence and managing cancer services sustainably with a growing, ageing population.

- **Recommendations on smoking, obesity and skin cancer should be amended to include a requirement to publish and deliver the strategies within a set timeline. The smoking strategy should include the target for NI to reach a smokefree future (adult smoking prevalence of 5% or less across all socioeconomic groups) by 2035.**
- **Campaigns raising awareness of cancer risk factors and targeting behaviour change must be developed with input from the target audience and funded to run across all mediums, with a targeted focus on specific groups in order to reduce health inequalities.**

Prevention strategies

All the recommendations in the 'Preventing Cancer' section are welcome. However, the recommendations which support **the development of new tobacco control and obesity strategies**

are particularly important and should be firmly committed to. These are the two biggest preventable causes of cancer in NI[2], with 17.5% of adults smoking[3] and 65.2% of adults overweight or obese[4], yet we have seen little strategic progress in recent years.

The cancer strategy is not the place to set out detailed actions that would ordinarily be included in area specific strategies and, as such, we are happy with the cancer strategy only focusing on top-line recommendations. However, the cancer strategy can be a vehicle to set out broad ambitions that the more detailed strategies can build upon. Whilst the cancer strategy recognises that other UK nations have a smokefree target, it does not commit to the introduction of one. Strong consideration should be given to **formally including the target for NI to reach a smokefree future** (adult smoking prevalence of 5% or less) by 2035, which would align with our ambition for a tobacco-free UK by this date.[5] This could be included as part of the recommendation on developing a new tobacco control strategy.

Firmer commitments should also be given on when each of the recommendations in this section will be delivered. The recommendations on smoking, obesity and skin cancer in particular should **include a requirement to publish and deliver the strategies within a set timeline**. Whilst the development of the next obesity strategy has begun, there is still limited details on the future of the tobacco strategy. It is therefore important that a specific date for the development, publication, and delivery of the new tobacco control strategy is outlined, as a hard deadline is important to avoid activity being delayed or deprioritised. We suggest that the tobacco strategy is published by the end of 2022.

When establishing timelines for implementing these recommendations, it is critical the biggest preventable causes of cancer in NI – smoking and obesity – are prioritised in order to have the greatest impact.

Awareness and behaviour change campaigns

We support the emphasis given to raising public awareness of cancer risk factors. These **campaigns should both raise awareness of risk factors and target behaviour change** (such as encouraging people who smoke to access stop smoking services). It is important that these campaigns are developed in collaboration with the public. Our patient panel raised the importance of using language which encourages action but avoids blame when discussing risk factors. It was also highlighted that messages must be brought to marginalised communities, noting that the COVID-19 vaccination programme can provide insight on how to effectively reach different communities.

Whilst funding will be required across this work, running awareness campaigns on the causes of cancer will have cost implications that must be accounted for. It is **critical that awareness campaigns have optimal media plans,** running across all mediums (including TV, online/social, radio, print), targeted approaches for specific audiences, and funded evaluation to assess impact. These campaigns will also need to run on a multi-year basis to have an effect, with unique creatives required to prevent campaign fatigue. Significant, ongoing funding will therefore be crucial to ensuring these campaigns are cost-effective and have the intended impact.

Early Diagnosis

We welcome the key themes and overarching proposals in the Diagnosing Cancer section. The broad ambitions identify several key areas of action for increasing timely, earlier diagnosis and improving diagnostic services. As the strategy has recognised, the success of each recommendation is dependent on timely access to diagnostic services which have the capacity to meet patient and health professional need. In particular, investment in **workforce and equipment will be vital to expanding capacity**. This must be a top priority when developing timelines and implementing the strategy, and will require major investment from the outset.

- **We support the strategy's recognition of the importance of raising public awareness of the signs and symptoms of cancer. This recommendation should be extended to include a commitment to encouraging timely help-seeking and making accessing primary care as easy as possible.**
- **We urge that the strategy goes further and sets out timelines for sensitivity and age-range changes to FIT bowel screening. We recommend a review of FIT screening modelling efforts undertaken in the other UK nations when assessing how and when changes to FIT screening are considered.**
- **The strategy should frame referral and recognition commitments through the overarching principle of ensuring timely recognition and referral for every patient. The core aim of delivering patient-centred care, with the right test delivered at the right time in the right setting, should inform the development of diagnostic hubs.**

Understanding the pathways of patients to cancer diagnosis is key for informing optimal service design, as the strategy recognises. It is essential that Pathways to Cancer Diagnosis reporting is repeated annually to measure how the strategy is supporting service improvement and the diagnosis of patients through screening and managed routes, and this should be formally committed to. The approach of other UK nations to pathway reporting should also be reviewed. Wales' Single Cancer Pathway and England's Faster Diagnostic Standard seek to better capture diagnostic pathways and use this insight to improve performance. Learnings from these approaches should inform efforts in NI to build on pathway reporting in order to improve the timeliness of investigation for all cancer patients.

The Diagnosing Cancer section should also contain **a clear commitment to reducing late stage diagnosis**. Instead of ending this section with the CRUK waterfall diagram (p. 46), it would be helpful to lead with this analysis in order to set the context for the recommendations, illustrating that no one solution will improve early diagnosis rates, but instead a range of initiatives are required. A commitment to reducing late stage diagnosis could be incorporated as part of the strategy's overall aims, amending the second aim to 'reducing late stage diagnosis and improving survival'. CRUK would be happy to support with the development of a target for reducing late stage diagnoses over the course of the strategy.

Awareness and behaviour change campaigns

Most cancers are diagnosed symptomatically and of these most are referred via primary care.[6] Commitment to government-funded activity to support timely help seeking, including public awareness and behaviour change campaigns, may contribute to reductions in late stage diagnoses. Encouraging help seeking is also crucial to the success and impact of other diagnostic interventions (such as NG12 implementation and diagnostic hubs). To maximise the efficacy of awareness campaigns, we therefore recommend that this section is extended to **include a commitment to encouraging timely help seeking and making accessing primary care and testing as easy as possible**.

Our patient panel highlighted the perception that GPs are under severe pressure, and that services are not open or easily accessible, which acts as a barrier to seeking help. CRUK research has also identified key barriers to help-seeking in Northern Ireland, including embarrassment talking about symptoms, worry what might be found, worry about putting extra strain on the health service, not wanting to talk to a receptionist about symptoms and worry about wasting the healthcare professional's time.[7] Reducing these barriers to help-seeking should be targeted as part of awareness and behaviour change campaigns.

It is welcome that the strategy recognises the importance of co-designing awareness campaigns with the cancer workforce and the public. To be most effective it is important that co-design involves health professionals from across the spectrum and a range of communities, including people who don't have cancer – a key insight group for this activity. Campaigns must be based on evidence of what works most effectively, as well as being targeted so not to exacerbate health inequalities.

The importance of data capture and evaluation are rightly noted – this will be essential for ensuring the campaigns are having their intended impact and reaching marginalised communities, and a **commitment to evaluation should be included** a part of the 'Be Cancer Aware' recommendation. As funding constraints have been the primary reason for pausing 'Be Cancer Aware' campaigns since 2016, it would also be beneficial to include a funding commitment in this recommendation to ensure the restart of these campaigns is a priority. The recent funding CRUK has received from the Cancer Charities Support Fund will support the delivery of this recommendation, which will take an insight led approach to messaging and creative to support earlier diagnosis of cancer in NI.

Screening

The strategy is right to recognise that screening is a vital tool for improving early diagnosis and that reducing variation in uptake is essential for improving outcomes for all. To strengthen the recommendation on increasing uptake across screening programmes, it should **focus on promoting informed choice**, rather than simply increasing uptake. CRUK advocates for the removal of barriers to participating in screening and supports informed decision making, rather than pushing people to participate.[8] We support the recognition that certain communities face greater barriers, and this will be important to address in screening initiatives to ensure health inequalities are not exacerbated.

Our patient panel reinforced the importance of continuing to promote informed decision making for screening. Common fears about cancer, unawareness of how screening can support better outcomes, and a lack of knowledge about the screening process were raised as barriers to participation. Clear communication about the aim of screening and what is involved could help lift these barriers. Our Cancer Awareness Measure also provides useful insight on the barriers people face to participating in screening – a breakdown of the results for Northern Ireland is available and we would be happy to share this data.

The introduction of the Facecal Immunochemcial Test (FIT) in NI at the beginning of 2021 was an important step in strengthening the bowel screening programme and supporting participation. The strategy acknowledges the importance of having plans in place to reduce sensitivity limits and extend the age range, but does not commit to this. **The strategy must go further and set out timelines for these changes**, outlining which change will be implemented first and when by. We note that England and Wales have prioritised age extension before sensitivity, with capacity being a key cause for not pursuing both optimising approaches concurrently. **We strongly recommend a review of FIT screening modelling efforts undertaken in the other UK nations and real-world data collection** when assessing how and when changes to FIT screening should be implemented. This will be critical to delivering an effective bowel screening service which will help increase early diagnosis of bowel cancer.

It is positive that the strategy includes a clear timeline for the implementation of HPV testing as the primary test in cervical screening. It would be beneficial if this commitment was included as an official recommendation to ensure this will get the funding and support required. NI is currently the only nation in the UK yet to introduce this, so it's essential that that these timelines are embedded in the strategy and adhered to. The strategy rightly acknowledge that pilots of HPV self-sampling are ongoing. This approach could mean that more people actively engage in cervical screening in the future, and so should be monitored.

We welcome the commitment to ensuring all UK NSC recommendations will be followed by NI, including the upcoming recommendation on lung screening. If the UKNSC recommends that lung screening be introduced, it is important that NI develops a clear and transparent plan to ensure they are not left behind the rest of the UK on the implementation and uptake of this programme. Learning from lung health check/lung screening programmes in other nations will also help accelerate delivery here.

Patient and population benefit, and not capacity implications, must be the primary factors in decision making on screening programmes. To enable this, a robust and funded workforce plan and adequate infrastructure capacity will be critical.

Reforming patient investigation and diagnostic services

The rest of the Diagnosing Cancer section covers several important factors, including the implementation of NG12 recognition and referral guidelines, pathways for people with vague but worrying symptoms and diagnostic centres. However, they are currently presented as separate issues rather than interlinked areas – referral guidance and pathways are closely connected and should be considered holistically. We therefore recommend that this part of the strategy is framed through the **overarching principle of ensuring timely recognition and referral for every patient**. The core aim must be the delivery of patient-centred care, with the right test delivered at the right time in the right setting. This principle is key and must be embedded in the strategy to ensure it is the basis of work in this area going forward. To achieve this aim, **clinical leadership will be critical in driving and delivering improvements and transformation**.

Engagement with the service and health professionals on the implementation of NG12 must be a priority and first step for achieving this ambition, with service configuration introduced over the longer term. In order to expedite the introduction of NG12, and ensure changes are sustainable, it may be advantageous to stagger the introduction by prioritising certain symptoms and pathways – this will require close engagement with healthcare professionals and service providers. It must also be recognised that **funding to expand diagnostic capacity will be essential** to success here. In England, GP referrals have been increasing by an average of 10% year on year, indicating the scale of potential resource implications for the system.[9]

The principle of patient-centred care should also inform the development of diagnostic hubs, based on best practice evidence and what is most suited for the region. We welcome the ambition to expand diagnostic hubs to include all patients with a red flag referral, helping ensure as many people are diagnosed as quickly as possible through this pathway. There is significant evidence from other nations and CRUK's own evaluation of diagnostic pathways[10] which can inform this work, and so we encourage consideration of this work in ongoing service redesign.[11][12] Health professionals (both from primary and secondary care) and patients should inform the effective design of these services and the pathways into and out of them.

The introduction of a 28-day diagnosis standard is an ambitious, long-term goal for the strategy. To ensure work towards this is sustainable, we suggest consideration is given to a graduated process, including starting with a lower target and aiming for a higher target over time – potentially in the region of 85%. Recent data shows that only 45% of cancer patients were referred via a Red Flag referral pathway in an audit of 164 patients diagnosed with cancer across six GP practices.[13] It is therefore welcome that the ambition is to include all people in this target, as otherwise there is a substantial proportion of patients who will not be monitored against this target and might fall through the net. As NI works towards the ambition of a 28-day diagnosis standard for all, learnings should be taken from the Single Cancer Pathway in Wales, which aims to capture all patients through their cancer waiting times system.

The triage tools section discusses a number of innovative tools which have helped UK nations manage services while dealing with the overwhelming pressure of the COVID-19 pandemic. Moving forward, it is important that the root causes of these challenges are dealt with, and **these tools are used where they can best support certain groups of patients**. We therefore advocate that the strategy leads this section with a principle that will determine the use of triage tools in the future. This principle should be framed around using tests for the right cohort for the best clinical utility purpose, and not driven by the intent to minimise service demand.

Treatment

The Treating Cancer section contains some important recommendations. It is welcome that current and future shifts in treatment options are acknowledged in future service planning, which is essential to ensuring innovation can be introduced. However, clarity on sequencing, implementation and funding is crucial here. These recommendations are broad in scope and success will depend on change in key areas first.

- **Quality data, such as clinical audits, must be at the heart of driving change in approaches to cancer treatment. The recommendations in this section do not go far enough to recognise this and overcome existing data challenges.**
- **It is concerning that there are no firm recommendations for radiotherapy included and we urge that this is amended in the final strategy document. In particular, we suggest prioritising recommendations on the rolling replacement of LINACs, and formally committing to a continual cycle of data review and examination.**
- **Stronger commitments need to be included to enable delivery of the vision set out for clinical trials. Consistent communication with patients and clear targets for improvement are a priority here.**

Priority areas

Quality data should be at the heart of driving change in approach to cancer treatment. Putting in place the required data governance, legislation, infrastructure and funding will be key to enabling comprehensive, timely and high quality data collection, linkage and access. At present, the absence of this has major implications for service delivery and access to treatment, hampering efforts to improve service safety, share best practice, reduce unwarranted variation, and provide real-world evidence on effectiveness of new treatment approaches. The recommendations in this section do not go far enough to recognise this and overcome existing data challenges.

There is significant evidence that clinical audits of certain disease areas are highly effective as a method of investigating treatment disparities and informing quality improvement. For example, in countries without high quality treatment monitoring, survival tends to be poorer for ovarian cancer.[14] It is therefore worth considering both whether NI should link with existing UK audits or start one independently.

Investment in **workforce and equipment will also be vital to achieving these recommendations**. This is recognised in later parts of the strategy, but it must be reinforced that without full funding wider change in treatment will be extremely challenging to implement. For example, the strategy rightly highlights that there must be the capacity in radiotherapy treatment units to accommodate the balance between reducing number of fractions and increasing complexity of treatment. To achieve this, radiotherapy units will need to be fully staffed, with appropriate training in place to support these developments, and have enough modern machinery to facilitate changes in delivery.

Both data and workforce are discussed below in the 'Implementing the Strategy' section, which further outline our recommendations for strengthening these priority areas.

Radiotherapy

It is concerning that there are no firm recommendations for radiotherapy included and we urge that this is amended in the final strategy document. In particular, we suggest prioritising two key points as recommendations.

Firstly, the strategy should **commit to the rolling replacement programme for LINACs**, combined with investment in both software and staff training, in order to ensure the required recurrent funding for this programme. Ageing LINACs are inefficient and can cause delays – funds to replace LINACs before they reach the end of their ten-year lifespan ensure the continued efficient delivery of treatment, with equipment able to adapt to innovation. As highlighted through our patient panel, up to date, efficient machinery is fundamental to ambitions of a world class service, and must be treated as such.

The strategy should also formally commit to a **continual cycle of data review and examination**, which is fundamental in providing learning opportunities which help to reduce cancer relapse, toxicity and improve quality of life.

Innovation

We welcome the commitment to developing a plan for the introduction and implementation of new surgical technology over the next ten years and emphasise the need to give consideration to how the plan might facilitate innovation in surgery as well funding, workforce and training, data, service organisation and delivery.[15] We also support the recommendation that cancer surgical services will be considered alongside emergency and elective services, and would like to see this strengthened to guaranteeing the delivery of cancer surgical services to ensure it receives focus throughout the duration of the strategy.

We welcome the recommendation to develop and implement prehabilitation and rehabilitation services on a regional basis for all those who will benefit. It will be imperative to undertake evaluation of existing services to ensure that services are delivering benefit and to inform any expansion or development of (p)rehabilitation programmes.

The shift towards more targeted treatment has the potential to improve treatment response rates and sometimes avoid harmful side effects to patients who cannot tolerate or are unlikely to benefit from more traditional treatments such as chemotherapy. The **commitment to delivering genetic and genomic testing in cancer pathways in line with NICE recommendation is therefore of high**

importance. Transparent funding and governance arrangements must be in place to support this recommendation, as genomics will become increasingly relevant to cancer care in the future. It also reinforces the importance of data collection, as optimal treatment can be guided by accurate data about the individual's tumour.

Eligible patients must be confident that they can access new precision medicines in NI, many of which will initially be made available for patients in England through the Cancer Drugs Fund (CDF). Positively, the Department of Health has committed to making CDF medicines equally accessible in NI in line with existing arrangements for NI endorsement of NICE recommendations, but it is key that funding for these and other innovative medicines accurately represents the expenditure required to meet patient need. This includes addressing the 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.

Supporting older patients

CRUK research shows that older patients are less likely to receive many different types of treatment than younger patients, and there may be some instances where they are not being offered curative treatment that could benefit them.[16] Whilst this is recognised in the strategy, we suggest the inclusion of a more specific recommendation which focusses on the better integration of geriatric services and a commitment to use appropriate methods to assess fitness for older and/or more complex patients. This could help to reduce the inequalities in treatment experience faced by older patients, and help ensure the strategy's aim of balancing patient need and ensuring appropriate treatment is met.

Clinical trials

Research is pivotal to developing our understanding of preventing, diagnosing and treating cancer. 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.[17] It is therefore welcome that the strategy recognises that research is not an 'add-on', but foundational to the delivery of a world-class cancer service. We recommend the inclusion of stronger commitments to delivering this vision, in order to **ensure research is a central component of the strategy**. The ten-year horizon provides scope to be more ambitious in this area and strive for transformation.

The strategy recommends increasing patient access to clinical trials, especially for children and young people affected by cancer. This is welcome and will be critical to strengthening clinical trials' beneficial impact on cancer patient outcomes in NI. Speaking to cancer patients, **poor communication on clinical trials access was raised as a major issue**. At present, patients highlighted that there is a general perception that clinical trials have a very limited presence in NI. It was also highlighted, that whilst not everything can be led from the region, links with activity across the rest of the UK must be stronger and more clearly communicated to patients. Clinical trials were identified as a source of huge patient benefit and hope, highlighting their importance not just for cancer research and future outcomes, but also for the patients participating in them.

In order to strengthen this commitment and ensure it delivers for patients, a target should be included that will enable measurement and evaluation of the strategy's performance in expanding access to clinical trials. We propose **a ten-year target that seeks parity of clinical trial access with England,** measured through the NI Cancer Patient Experience Survey with progress benchmarked every two years.[18] This means that the proportion of NI cancer patients being asked about research participation should increase overall from 15% (reported in NI, 2018) to around 31% (reported in

England, 2019).[19][20] In the future, clinical trial access could be impacted by the NI Protocol and decisions at Westminster and Brussels which are outside of the Department of Health's control. It is important that throughout potential changes, it remains a priority to minimise any disruption to patient access.

The strategy acknowledges that NI spends comparatively less on clinical research per capita compared with the other UK nations and that this is likely to worsen as medical research charities look to reduce their spending in response to the pandemic's impact on fundraising. If it is to achieve its goal of increasing patient access to clinical trials, and its broader strategic aims for cancer outcomes in NI that research contributes to, **the strategy must recognise the need for increased public investment in NI-based cancer research**, with a view to committing that money within the first year of the strategy. We recommend an uplift in long-term funding for the HSC R&D budget. At a minimum, this funding increased should be in-line with broader uplifts in public R&D investment and keep pace with future increased in inflation.

Implementing the Strategy

- **It is essential that a robust monitoring and evaluation framework is developed. The strategy commits to reporting at year 3 and subsequent intervals, which must build in opportunities to review progress and adapt the strategy as required, ensuring it remains relevant and impactful to 2031.**
- **We strongly support the commitment to develop and implement a regional, multi-professional workforce plan. As is recognised throughout the strategy, a fully funded workforce that is equipped to meet both current and future patient need will be critical to enabling success, and it must be an immediate priority for action and investment.**
- **More detail is required on the specific initiatives which will deliver ambitions for data. Multi-year funding for the Northern Ireland Cancer Registry (NICR) should also be secured so that it can plan more strategically and build its capacity accordingly.**
- **There is no tangible plan to build research capacity – we recommend that the strategy incorporates key recommendations from CRUK's *Bench to Bedside* and *Creating Time for Research* reports in order to increase access to research and accelerate improvements in patient care.**

Governance

The establishment of a Cancer Programme board, with strong clinical leadership, to oversee strategy delivery is very welcome. As we have advocated, bringing the right people together to lend their expertise to the strategy's development and implementation including clinicians, IT and infrastructure experts, service planners, third sector partners and members of the public and patients, will be critical to delivering complex and ambitious change across services. It is important that **a 'clinically-led' Cancer Programme includes representatives from primary, as well as secondary, care**. GPs play a vital part in cancer diagnosis, and their involvement is especially important when it comes to developing, reviewing and implementing referral pathways for cancer, as GPs refer patients into these. Meaningful clinical leadership and engagement will require resourcing.

The International Cancer Benchmarking Partnership (ICBP) examined the role of leadership in cancer care systems, which can inform the development of the governance arrangements. Their study identified several factors that are important for improving outcomes, including political, intellectual, and clinical leadership, and a coherent vision for leaders across the system.[21] Learnings from the other UK nations can also help inform governance arrangements. For example, the Scottish Cancer Taskforce, responsible for overseeing the actions in the *Beating Cancer: ambition and action* strategy, was empowered with oversight of all issues relating to cancer in Scotland.[22]

We would also emphasise that **research must be well-represented on this Board**, as research will play a critical role in achieving the strategy's goals for patient outcomes and cancer survival. For example, there should be a representative from the Belfast Experimental Cancer Medicine Centre – the Centre is a critical component of NI's cancer research infrastructure, and is also connected to the wider Experimental Cancer Medicine Centres (ECMC) Network. The research representative(s) should engage with stakeholders across the research landscape, as well as in other parts of the pathway.

The strategy commits to the introduction of a robust suite of key performance indicators (KPIs) and reporting at the end of year 3 and subsequent intervals, as well as an annual report. It is essential that the year 3 and year 6 reporting involves a meaningful review of the strategy, in order to reflect progress and appropriately adapt to the changing cancer and health landscape. The strategy must then be **updated following assessment to guarantee that it remains relevant** and impactful to 2031.

Workforce and training

It is essential that NI addresses the challenges facing the cancer workforce. A fully-funded workforce that meets patient need will be fundamental to ensuring the proposed changes can be implemented effectively across the cancer pathway and enabling the transformation of cancer outcomes – without action and funding, it is difficult to see how meaningful progress can be achieved. **The dependencies created by a strong workforce mean it must be an immediate priority for action and investment**.

We strongly support the commitment to develop and implement a regional, multi-professional workforce plan to ensure NI has skilled staff available to deliver cancer services for the future. However, the detail on workforce expansion in the strategy is limited, given the scale of the challenge. We appreciate that this is because much of the detail will likely be in the forthcoming workforce plan. Even accounting for that, there are some notable gaps in the strategy, including the importance of a fully-staffed and well-trained primary care workforce, which is vital for appropriate recognition and referral of patients with cancer symptoms.

To ensure it is equipped to deliver the required change in the cancer workforce, the workforce plan should outline:

- The gaps in the key cancer professions, including modelling of how supply and demand for cancer workforce will change moving forward, based on projected demographic changes, the growing prevalence of cancer and likely impact of technology;
- How much funding will be available to implement the plan, and if it will be sufficient to deliver on the identified gaps – long-term, sustainable funding in medical training and education will be essential for growing the cancer workforce;
- How to tackle the barriers to adopting skill-mix approaches to workforce planning in both the diagnostic and treatment workforce;
- A plan to harness the opportunities presented by, and mitigate against the risks posed by, future workforce trends, e.g., flexible working, an ageing workforce, retention, training and development;
- How to ensure workforce has the capacity to carry out clinical research, and;

- How the workforce will be prepared for future innovations, in particular genomics, which will require training and investment.

The adoption of skill-mix approaches has rightly been identified as a way to align the workforce with the needs of cancer patients, increasing the workforce's capacity and improving the experience of staff. The strategy focusses on skill-mix in oncology teams. We suggest that this part of the strategy also discusses skill-mix in diagnostic services, given that this can increase capacity in the areas of known shortages. For example, the use of reporting radiographers to report on images is well established across the UK, helping to ease the burden on radiologists by taking on interpretation duties for some images on a chosen speciality.[23] Skill-mix approaches can also support the primary care workforce – with additional roles taking on some responsibilities traditionally taken on by GPs. Skill mix in primary care could help free up GP time to work on more complex, potentially cancer, cases. Increasing the number of different roles in primary care could also provide patients with increasing touchpoints, with appropriate training provided to ensure these roles have the skills to identify possible cancer symptoms. As workforce shortages are particularly acute in diagnostics, it would be beneficial to target skill mix measures to increase capacity here as a priority – including imaging, endoscopy and pathology.

Importantly, the strategy recognises the benefits research participation has to offer health staff, including for their expertise, wellbeing and retention. As such, it is a gap that the strategy doesn't then build on this insight by committing to include research in workforce planning and decisions, both at a national and Trust-level. *Creating Time for Research* discusses the importance of increasing the visibility and attractiveness of research engagement, which can be integrated into workforce hiring, retention and development strategies.[24] This strategy should therefore commit to incorporating research into its workforce plan, including highlighting its capability as a means of upskilling, increasing wellbeing and retaining expertise.

Data & Encompass IT system

High-quality, accessible data will be essential to driving improvement in cancer services in NI. As the strategy rightly recognises, data must underpin evidence-based and informed decision making across the system. It must be treated as a priority for implementing and evaluating the strategy.

Ambitions for data in NI

We support the recommendation for a formal review of the Northern Ireland Cancer Registry's (NICR) role and responsibilities and are ready to support the development of an approach to this. Equally, we recognise that a great amount of work has already been undertaken by the registry and stakeholders to highlight the challenges and opportunities facing cancer data in Northern Ireland, and hope these findings provide a strong basis for initial actions and any future review. **There is sufficient information and agreed recommendations to begin implementing changes now**.

Cancer Research UK's aim is for 'data equity' across all four UK nations, and, to varying degrees, each UK nation faces the challenge of balancing the desire for high quality and timely data. To this end, the language and overarching approach to data in the strategy is positive. However, there needs to be more detail about specific initiatives which will deliver these overall aims aside from the Encompass programme. We would also welcome some more specific strategy ambitions for cancer data in NI.

Effective funding will be critical to enabling this work. It would be helpful to understand what funding the NICR will receive, particularly to ensure that the acceleration of work to implement

Encompass does not divert crucial funding and attention from securing and enhancing core cancer surveillance functions. In particular, **we would welcome a multi-year or recurrent funding settlement for the registry,** so it can plan for more ambitious, longer term initiatives and build its capacity accordingly.

Encompass

The Encompass IT system has the greatest potential to impact on the ability of the registry to collect cancer data. The strategy **must include greater detail on how Encompass is working with the NICR to align current and future requirements**, to ensure that the challenges and opportunities of cancer surveillance are addressed through this well-funded project. It would also be helpful to understand how Encompass will facilitate research (such as by providing the data governance and security required to support secondary uses, in anticipation of legislation being introduced) alongside it's more explicit aim of supporting the provision and monitoring of care. Patients have highlighted the importance of this, with a call to gaining the power to reduce the barriers surrounding the use of their own data in research in order to improve outcomes.

Use of data

The establishment of a regulatory and legislative framework for the secondary use of data is essential. Not only is it critical to the functioning of the registry, but also for enabling and encouraging research and the analysis of diagnostic and treatment data. At present, there is some concern about the vague timeline referred to in the strategy for this legislation. We would welcome assurance that systems are in place to implement the legislation, with clear timeframes.

It is right to acknowledge fears of privacy and data protection in the strategy, although the solution for this should not solely focus on 'good governance'. As has been seen with recent concerns about access to and use of GP-held data in England[25], **ongoing, meaningful communication and engagement with patients and public** is equally important and essential in order to build and maintain public trust.[26] Our patient panel also highlighted the importance of transparency and open communication on data management and information, to build trust in and comfortability in using electronic systems. This will also need to be considered as the 'patient portal' is rolled out as part of the Encompass programme. Patient choice must remain central here, with confidence built in how data is being used, and ensuring a clear point of contact to discuss both the information available on the system, and any concern about how it's being used.

Research

The strategy rightly identifies key considerations for cancer research in Northern Ireland – it's importance for patient outcomes, the lack of protected time and resource for the workforce to engage in research, and the benefits of collaboration between different types of funders. However, it currently **lacks a tangible plan to build research capacity**, which is essential to achieving the strategy's long-term goals for patient outcomes.

We strongly recommend that the strategy adopts the proposals put forward in Cancer Research UK's *Bench to Bedside*[27] and *Creating Time for Research*[28] reports. *Bench to Bedside* analyses the state of the medical research environment in Northern Ireland and identifies policy actions to optimise it. Several factors were identified that enable a high-quality research environment, including: leadership, policy and collaboration; funding; infrastructure; workforce; and patient access to research. *Creating Time for Research* focusses specifically on improving the capacity of healthcare staff to conduct research. It makes recommendations across four broad themes: increasing support and resources for research staff and infrastructure, addressing disparities in research activity, developing career pathways for entering and progressing in research, and strengthening national- and organisational-level research cultures. Incorporating findings from the report into the strategy will help drive the recommendations to increase access to research and accelerate improvements in patient care.

The Early Detection and Diagnosis (ED&D) of Cancer Roadmap, developed by CRUK, could also help inform plans to building research capacity in NI.[29] As well as the outcome benefit of focusing on the ED&D of cancer, there is a globally rising tide of industrial and private finance interest in research related to ED&D technologies. The Roadmap highlights a number of barriers currently hindering ED&D research and development (R&D), including challenges with data access for ED&D research, limited research funding and infrastructure and a lack of incentives for investing in new ED&D approaches. It also sets out key actions required to prioritise, incentivise and embed early detection and diagnosis (ED&D) in research and development. Showing leadership in ED&D research, including through investment will help advance progress so fewer cancers are detected when advanced, and could create a thriving sector in the economy.

About Cancer Research UK

Cancer Research UK (CRUK) is the world's largest cancer charity dedicated to saving lives through research. We support research into over 200 types of cancer, and our vision is to bring forward the day when all cancers are cured. Our long-term investment in state-of-the-art facilities has helped to create a thriving network of research at 90 laboratories and institutions in more than 40 towns and cities across the UK supporting the work of over 4,000 scientists, doctors and nurses. In 2020/21, Cancer Research UK invested £421 million on new and ongoing research projects into the causes and treatments for cancer.

Produced by colleagues in the Policy, Information and Communications Directorate at Cancer Research UK. For more information, or any questions, please contact Rani Govender (Policy Advisor – Cancer Transformation) – Rani.Govender@cancer.org.uk.

Appendix

Specific recommendations

The following table outlines specific amendments which would strengthen the strategy.

Page	Section	CRUK recommendation
6	'The International Cancer Benchmarking Project (ICBP) Module 1 report showed cancer survival in Northern Ireland (NI) to be behind other parts of the UK, Australia, Canada, Denmark, Republic of Ireland, New Zealand and Norway. Northern Ireland consistently ranked between 8th and 10th out of the 12 jurisdictions involved.'	We no longer refer directly to Module 1, as that covered 1995-2007. This should therefore be changed to '*The International Cancer Benchmarking Project (ICBP) has shown cancer survival in Northern Ireland…*' The full reference for this work is: Arnold, M. et al. (2019). Progress in cancer survival, mortality, and incidence in seven high-income countries 1995–2014 (ICBP SURVMARK-2): a population-based study, The Lancet Oncology. DOI: https://doi.org/10.1016/S1470-2045(19)30456-5 We also recommend changing the wording of the last sentence as follows to most accurately reflect the ICBP results: The UK overall had the lowest 5-year survival for 5 of the 7 cancer sites studied (colon, rectal, lung, pancreas, stomach) for the period 2010-2014. Between the UK nations, Northern Ireland had the lowest survival for rectal, lung and pancreatic cancers.
8	'To co-produce a cancer strategy which will focus on fewer people getting preventable cancers; **more people surviving for longer** after diagnosis; and improve the experience of care for all cancer patients in Northern Ireland by Dec 2021'	They key aim here must be the meaningful extension of life. In order to ensure this is the focus, this is best phrased as 'more people diagnosed earlier, and more people surviving longer as a consequence'.
8	'Reliable data and informatics'	Suggest amending to 'timely and high quality data and informatics'.
11	Cancer in NI – Cases	It is worth adding stage and survival by stage data here. Importantly, this will outline the key data which has been collected in NI and has been central for informing strategy development, particularly the Diagnosing & Treating Cancer recommendations.
15	Health Inequalities	It is right to draw attention to tackling health inequalities. As they cut across the pathway, we

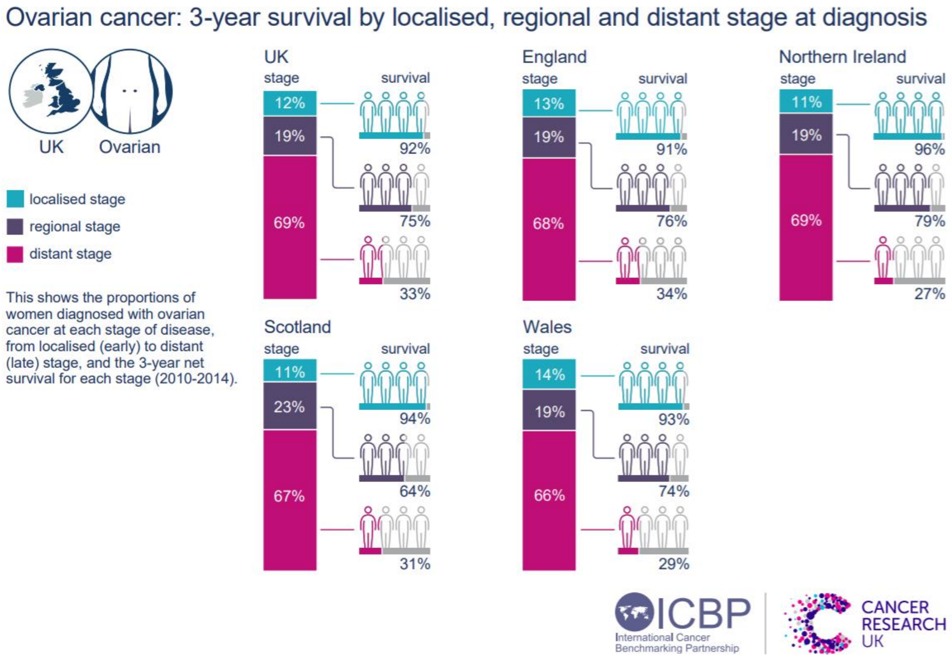
		suggest moving this part into the 'Cancer in NI' context section.
33	'We will develop measures to increase uptake of all cancer screening programmes, particularly in seldom heard communities.'	The wording in this recommendation is unclear. We suggest that this is split into two separate recommendations: - Designing and implementing interventions which reduce unnecessary barriers to screening uptake and support informed uptake - Monitoring uptake through data collection and evaluation, including sociodemographic breakdowns
35	'There are other emerging tests being rolled out at pace elsewhere in the UK, for example **CT-capsule endoscopy'**	It is unclear whether this is referring to CT colonography or colon capsule, and should be amended accordingly. We suggest the focus in this part is on monitoring developing pipelines and outlining the purpose for implementing these tests. For example, CT-colonography can be a preferred method for vulnerable population groups.
38	Before 'In 2015, the National Institute for Health and Care Excellence (NICE) launched their newest...'	A sub-heading is missing at the end of the screening section, before this new part. We suggest 'Symptomatic presentation – referral and recognition' is used.
44	Paragraph on GRAIL, beginning 'Grail is a US/UK company whose Galleri multi-cancer blood test will be piloted by the NHS on 165,000 people in England.'	We recommend that direct reference to GRAIL is removed, and instead there is a broader discussion of liquid biopsies and innovation. This is important for ensuring the strategy's continued relevance depending on future developments and innovations.
48	Recommendations on cancer surgery.	We recommend the following sources are considered to ensure the best possible evidence is considered when developing approaches to centralisation and specialisation: National Cancer Registry (2019). Cancer care and survival in relation to centralisation of Irish cancer services: an analysis of National Cancer Registry data 1994-2015. https://www.ncri.ie/sites/ncri/files/pubs/CancerCentralisation_NCRI_Jan2019_fullreport_29012019_final.pdf

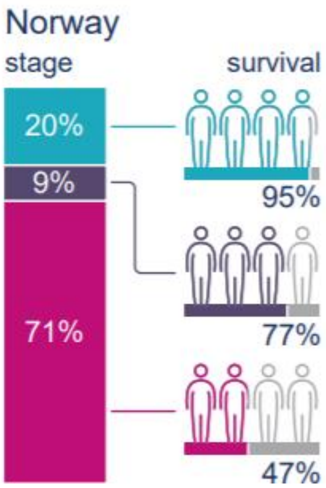
		Reorganising specialist cancer surgery for the 21st century: a mixed methods evaluation (RESPECT-21) https://www.ihpo.manchester.ac.uk/research/projects/respect-21/
54	‘We will implement in full the recommendations of the Oncology Service Transformation Project and the Oncology Haematology stabilisation plan by 2026.’	The Oncology and Haematology Stabilisation Plan proposes an investment of £8.56m across oncology services and £3.63m across haematology services over the next 2 years (up until March 2022). It is unclear if funding will come from either the annual healthcare budget or strategy funding after March 2022. We encourage providing clarity on funding for the implementation of the Oncology and Haematology Stabilisation Plan beyond March 2022.
61	‘We will consider the development of CAR-T services for NI.’	We would encourage that this recommendation is strengthened to clearly commit to a plan for developing CAR-T services in NI.
74	‘We will ensure that an effective Multi-Disciplinary Team meeting is held for all people diagnosed with cancer including cancer of unknown primary and metastatic disease.’	This recommendation should be strengthened and made more specific. For example, including a commitment to streamlining MDT meetings, and improving the quality of discussions. Reference: Gray, R., Gordon, B., Meredith, M. Meeting patients’ needs: improving the effectiveness of multidisciplinary team meetings in cancer services, Cancer Research UK. Available: https://www.cancerresearchuk.org/sites/default/files/full_report_meeting_patients_needs_improving_the_effectiveness_of_multidisciplinary_team_meetings_.pdf

Graphics

The below graphic presents survival by stage data for ovarian cancer from the ICBP. This information is an example of the data which should be analysed to understand where NI may be lagging behind and should take action.

We can share more infographics from the ICBP if useful.





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