Cancer Strategy for Northern Ireland 2021 – 2031

Public Consultation Report

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Introduction

In August 2021 the Department of Health (DoH) published the draft Cancer Strategy for Northern Ireland for public consultation following an extensive period of co-production. During the consultation there was significant engagement with stakeholders from various sectors and backgrounds which resulted in a robust level of response and thought provoking breadth and depth of feedback for consideration.

During the course of the consultation we received 107 responses, this includes an agreed extension period up to 12 weeks and one response received after the closing date. In addition 145 stakeholders attended three virtual public consultation stakeholder events to provide their responses to consultation. Each consultation response has been given due consideration, resulting in a number of changes to the final strategy document as well as providing valuable insights that will be considered as part of the implementation of the Strategy.

This report provides a summary of the comments made in response to the consultation, both in virtual consultation events, and in formal consultation response submissions to the Department. It also highlights how issues raised during the consultation have been considered and addressed in the revised strategy document.

Background

The publication of a 10 year Cancer Strategy was identified as an immediate priority of the Northern Ireland Executive in New Decade, New Approach (NDNA).

The advent of the global COVID-19 pandemic has also changed the picture of cancer services in Northern Ireland. The possibilities offered by new and novel

technological solutions as embraced during the pandemic to enhance access and choice and improve outcomes are also a key focus of the draft strategy.

The Cancer Recovery Plan published in June 2021 by the Health Minister, Robin Swann MLA, not only addresses immediate service improvement requirements but also acts as precursor to the new strategy and addresses around 70% of the first 3 years of strategy recommendations.

The draft strategy had a central vision to ensure that everyone in Northern Ireland, wherever they live, has equitable and timely access to the most effective, evidence-based referral, diagnosis, treatment, support and person centred cancer care. Its ambition is to have a world class service based on improving outcomes for everyone diagnosed with cancer. Feedback from the public consultation has enabled DoH to strengthen the revised strategy to strive for this aim.

Co-Production of Draft Strategy

The strategy was co-produced with input from 583 people. The development of the strategy meaningfully included service users and carers, clinical specialists and charities within the regional structures and through ongoing engagement with key stakeholder groups. This included co-production of the recommendations through the seven sub-groups which were co-chaired by people with lived experience; direct engagement with people with lived experience through engagement events and workshops discussing the cancer strategy and the specific recommendations by speciality.

The cancer strategy development was led by a Steering Group which was co-chaired by the Chief Nursing Officer (CNO) and a person with lived experience. It was

supported by seven sub-groups; all co-chaired by people with lived experience exploring; prevention; diagnosis and screening; treatment; care and support; living well; palliative and end of life care, children and young people. Each sub group looked at issues affecting that part of the cancer journey while a stand-alone group was established for children and young people. Sub-group members represented a number of organisations including Health and Social Care (HSC), Third sector organisations including cancer charities, Public Health Agency (PHA) and DoH.

A lived experience group was established; this was chaired by the co-chair of the steering group and included sub-group co-chairs and the DoH cancer strategy team. The group facilitated input from people with lived experience and their carers in the development of the new cancer strategy by sense checking and feeding back to the steering group thoughts on output from the sub-groups.

A service user and carer reference group was also established, in it included 27 people with lived experience. Membership of the group represented different geography, demographics and cancer specialities across Northern Ireland. This group was openly recruited via advertisement regionally through the Patient Client Council's (PCC) Make Change Together platform. The group have participated across a range of activities, including an induction and regional workshop as well as attending workshops and providing specific feedback on the draft recommendations by speciality.

DoH also worked directly with Northern Ireland Cancer Network (NICaN) to engage with third sector organisations and ensure maximum input from those with experience of both delivering and using services right across the cancer journey. A

series of meetings took place as part of on-going strategy development and pre-consultation engagement.

Pre-Consultation engagement

Pre-consultation played an important part in the development of the strategy and recommendations. It provided the opportunity to test the content with wider stakeholder groups who have an interest in and experience of cancer services. This process allowed DoH to identify areas for further development and highlighted issues that required further scrutiny in advance of full public consultation.

Extensive and targeted stakeholder engagement and pre-consultation took place, resulting in 39 meetings with 450 additional stakeholders. It included engagement with a variety of stakeholders including the All Party Cancer Group, NICaN Cancer Charities Forum, the Less Survivable Cancers Taskforce, Teenage and Young Adult Clinical Reference Group, people with lived experience and their carers, HSC Chief Executives Forum, primary and secondary care clinicians. This led to a number of changes being made to the draft strategy document which was presented for full public consultation.

Consultation process

The aim of the consultation process was to provide an opportunity for as many people as possible to share their views and feedback on the co-produced draft Strategy and its vision, themes and actions.

The consultation was launched on 25 August 2021 and ran for 8 weeks until 20 October 2021. The Department was specifically consulting on the draft Cancer Strategy 2022-2032, and three impact assessment screening documents; Equality and Human Rights, Regulatory and Rural Needs. An additional four weeks was

added to the consultation for completion of EQIA responses, until 17 November 2021.

Requests for meetings with individuals and groups were facilitated and requests for additional response time were accommodated.

All documentation was published on the Department's website. The draft strategy was available in alternative formats on request. Supporting documentation was provided in the form of:

- A consultation document providing supporting background information; and
- An Easy Read version of the draft Strategy

Views were sought on 5 questions covering 67 high-level recommendations over 4 themes to take forward significant strategic change over the next decade. These were:

1. Preventing Cancer
2. Diagnosing and Treating Cancer
3. Supporting People
4. Implementing the Strategy

Respondents could respond to the consultation via a number of routes:

- By completing the online questionnaire provided on the Northern Ireland Government Citizen Space website;
- By completing the MS Word response questionnaire and either posting or emailing to the Department;
- By submitting views and comments in an alternative format, e.g. an email, letter or free submission.

Public Consultation Events

A number of virtual consultation events were also held to support wider engagement and consultation with stakeholders. All events were advertised on the Department's website, via social media, the Patient and Client Council and other Networks. 210 people registered, of those 145 attended the events.

Three online consultation engagement events took place on the following dates and times;

- Tuesday 5 October 2.00 - 3.30pm;
- Thursday 7 October 11am - 12.30pm; and
- Tuesday 12 October 7.00 - 8.30pm.

These events were organised by the DoH, advertised through Eventbrite and delivered via the Zoom platform. Sessions were facilitated by the HSC Leadership Centre.

Each session lasted approximately 1.5 hours and over the three workshops, a total of 145 people attended, including representatives from; HSC organisations, members of the public, service users, carers, Third Sector organisations, Education, Pharmaceutical Organisations, Local Government and other stakeholders.

The online engagement events included:

- Strategy overview, principles and timeline delivered by the CNO;

- Overview of the key themes, context and recommendations from the cancer strategy co-chairs;
- Overview of implementation by representatives from the DoH.

The engagement exercise focused on the key themes and recommendations and used the same questions as the consultation questionnaire. The discussion was led and facilitated by the workshop contributors and in smaller breakout rooms of approximately 15 people. Attendees had an opportunity to share their views and suggestions. These findings were captured by scribes and key points shared by the facilitators during each workshop.

NICaN engagement event

NICaN also hosted an additional consultation event for clinical staff where senior officials from the cancer strategy team and cancer strategy sub group leads received feedback on the strategy.

Consultation response summary

During the consultation process, formal written responses to the consultation were provided in a variety of formats, including free submissions, email/hard copy response questionnaires, and via Citizenspace. In total, 107 written responses were received; of those, 90 were responding on behalf of an organisation. An additional 145 stakeholders attended one of three online engagement events.

The majority of the respondents via Citizenspace provided an answer to each of the 5 questions asked. The majority of the general responses were received via email and many did not use the consultation questions to frame their response, nor did they all provide an answer to each of the questions asked. The analysis set out in the sections below is therefore based on those responses who did provide a direct answer to the questions asked. However, the qualitative analysis of comments takes cognisance of all responses received, regardless of format.

Responses were analysed using a discourse analysis methodology. This analysis indicated a generally positive view of the content of the draft Strategy, with over 88% of responses received via Citizenspace being assessed as positive. Responses also provided valuable insights and suggestions to strengthen various elements of the strategy and implementation plan.

The analysis will provide a summary of the responses received by theme, highlighting issues raised and sharing quotes to illustrate feedback received. It is not possible to include quotes and full details of responses here, however the summary provides an overview of wider feedback received. The themes used are presented in line with the questions asked during the public consultation and engagement events.

A table outlining how DoH have considered and included the consultation responses in the revised strategy is presented at the end of the analysis. It reflects the complex nature of the responses received across all of the consultation questions and uses the 'you said, we did' format to summarise what consultees have identified as important and how that is being addressed.

Theme 1. Strategic Priorities

It was clear from the feedback received across all channels that there was broad agreement with the priorities and recommendations set against each of the key themes.

"We welcome the strategy and the opportunity to feedback. The overall aims of the strategy; to reduce the number of people diagnosed with preventable cancers, to improve survival, and to improve the experience of people diagnosed with cancer, are entirely appropriate. It may be helpful to explicitly state the aim of improving early diagnosis. It is implicit within the document, but not clearly stated at the outset and can become somewhat lost in the narrative. The overall approach in terms of the work stream areas is logical and in general, the direction of travel reflects conversations within the broader service." NICAN Clinical Reference Groups

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"There is need for a strong and clear acknowledgement of the current state of play, particularly in terms of workforce capacity and the ongoing impact of COVID19. The strategy was in development before the Covid pandemic, there is need for acknowledgment of the difficulties that the pandemic has posed and how the service needs to be prepared for such events. The public need to understand that improvements, most of which rely on workforce, will take some years to realise (due to the workforce /training time needed)." NICAN

"The overall consensus coming from the workshops is that people strongly agree with the contents and recommendations set out in the draft 10-year strategy."

"It is a very comprehensive document which I feel takes into account all aspects of cancer care and gives scope for improvements/developments in practice and technology moving forward." Individual response

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It was also evident that respondents recognised the ambitious nature of the strategy and the requirement for key drivers to support implementation of the strategy if the stated aims are to be achieved within 10 years. These included greater partnership working, finance, workforce, education, availability of technology, data and greater links to existing strategies with relevance to cancer services.

"The strategy is highly comprehensive and examines closely all aspects of patient care and areas that need to be addressed. The focus is all in the right areas, and the identified strategic priorities highlighted are all based on the best intent. As with all strategies, it is the implementation that is the key. Adoption of a whole system collaborative approach is clearly a thread that runs through the document. By identifying all the patient touchpoints and all aspects of care, from prevention to supporting people to die well, the strengths and challenges in the system have been highlighted." Teva UK Ltd

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"We support the aims of the Cancer Strategy and agree that the strategic priorities have been correctly identified. However, we feel there must be more prominence given to the facilitation of early diagnosis of cancer. We feel this rests predominantly with general practice and it must be adequately supported to provide this. We are acutely aware that the Cancer Strategy is currently unfunded and there is no financial capacity in current budgets to meet the priorities. If the Cancer Strategy is to make difference to the lives of people living with cancer and the healthcare professionals who care for them, it must be funded fully and sustainably." Royal College of General Practice

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"We welcome the threefold aims of the strategy but emphasis that these ambitions will need to be underpinned by an implementation plan that must achieve earlier diagnosis and ensure patients receive treatment quickly. Part of this should include a push to increase the availability of cancer treatments, including those which are vital for early-stage cancer cure. Radiotherapy must be at the heart of that push. There has been a revolution in radiotherapy technologies around the world and it is vital that patients in Northern Ireland also see this benefit. if we are to achieve the strategic goals of the Northern Ireland Cancer Strategy, radiotherapy must receive the funding and support to play its part." The Catch Up With Cancer campaign and Action Radiotherapy

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Respondents highlighted the impact of COVID-19 and sought assurances that this would not further delay the implementation of this strategy.

"I agree with the priorities. However I think that cancer services should be given equal if not great priority over Covid-19." Individual response

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"**Cancer patients, and particularly for those of us with advanced disease, have been significantly disadvantaged in so many ways due to covid-19**.

"BDA NI … recently presented to the NI Assembly's All Party Group on Cancer regarding the significant impact COVID has had on reduced head and neck referrals, in addition to the considerable challenges that pre-date the pandemic around a cancer that is on the increase.

COVID-19 has significantly reduced the numbers of patients dentists are able to see in practice due to higher infection prevention control measures, fallow-times, enhanced cleaning, PPE and applying social distancing, therefore our challenges around oral cancers are perhaps greater than ever.

A joint piece of work involving BDA, Cancer Focus NI, MSD, Prof. Mark Lawler, NI Cancer Registry and others is being taken forward to examine how we can improve patient outcomes in Northern Ireland for those with Head and Neck Cancer. We are looking at patient pathway mapping, identifying where and why there are delays in diagnosis and treatment." British Dental Association NI

Theme 2. Preventing Cancer

Consultation responses identified that cancer prevention should constitute a significant part of the strategy, however highlighted the importance of how this information is presented.

“Prevention section too long introduces feelings of guilt and blame” Individual response

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“Prevention recommendations should include specific actions such as the development of a range of community based commissioned services to aid and support patients and increasing public awareness in these key public health areas.” Community Pharmacy NI

Consultees across all response channels challenged DoH to strengthen the commitment to cancer prevention within the strategy. Issues such as the importance of clear language and consideration of tone when discussing prevention, appropriately targeted public health campaigns, use of a wide range of media and inclusion of social media, and consideration of specific cancers along with greater emphasis on health inequalities and better to links to existing public health and related strategies.

"The commentary associated with the section relating to preventing cancer as set out on pages 14-30 of the consultation document is to be commended for providing some useful contextual information, recognising the link between cancer and health inequalities, and identifying the main known modifiable risk factors, specifically smoking, obesity, diet and physical activity, ultraviolet radiation, alcohol, infections, oral health, and environmental pollution (including radon).

In general terms, the RCN endorses the various recommendations set out in this section…The recommendations under the three main themes of prevention, diagnosis and treatment, and supporting people bring to life and mirror the cancer pathway upon which patients find themselves, irrespective of tumour site. However, the wording of these recommendations is often imprecise."

Air pollution is discussed as it pertains to its role in the development of cancer. This section failed to recognise the weight of scientific evidence that demonstrates the effects of many endocrine disrupting chemicals (EDCs) that pollute the air and are associated with an increased risk of developing cancer. Pink Ladies Cancer Support Group.

"Another participant working in a local authority told of how they were heavily involved in prevention when it came to air pollution. However, they felt as though no action was taken towards this concern. This could be due to Northern Ireland currently not having a dedicated strategy to reduce air pollution." Pubic Consultation engagement event report

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"Recognition of improved lifestyle for Secondary Prevention is welcomed, with a clear objective of providing targeted information and support to live well and reduce risk. The charitable and community sectors are well placed to help deliver on these proposed activities and should be fully engaged with, and supported, to do so. Strategies should be co-designed and integrated to ensure maximum impact. However, greater coordination and sharing of information is required with cancer charities and between cancer charities to ensure alignment and consistency of message." Action Cancer

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Theme 3. Improved outcomes

The strategy's emphasis on diagnosing and treating cancer is supported by respondents.

"The hardest to treat cancers, such as pancreatic cancer should get specific focus on symptom awareness to encourage an earlier diagnosis." Individual response

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"A recommendation that people who have cancer are diagnosed as quickly as possible is welcomed. References to better integration of older people's services with oncology and haematology, better collaborative working between cancer services, learning disability and mental health services, are commended, as is the

recommendation to ensure the development of appropriate pathways and services for older people with cancer, rarer cancers, teenage and young adults and people seldom heard. Cancer affects people of all ages, and the strategy considers this. The recommendation to explore the potential for greater collaboration between Northern Ireland, Great Britain and the Republic of Ireland in the provision of children's oncology services is welcome." South Eastern Local Commissioning Group

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A range of views were expressed in relation to the level of detail within this section of the strategy with some consultees expressing disappointment that specific cancers were not directly referenced.

"Metastatic disease is poorly covered in the document. This is disappointing in the extreme, given the lack of awareness of metastatic cancer in the general public…. It is probable that there is similar or an even greater lack of knowledge of metastatic disease relating to other cancer types. There is a need to highlight the difference between primary and secondary disease, collect and review data pertaining to secondary disease, review treatment approaches and improve outcomes for metastatic disease." Beaconbridge Secondary Breast Cancer Group

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"The identified focus on diagnostic pathways, symptom awareness, screening tools and addressing cancers with non-specific symptoms to drive earlier diagnosis and improve outcomes is welcome – but brain tumours unfortunately represent a unique

diagnostic challenge, and it is therefore important that specific focus is set out in the strategy to achieve long-awaited progress alongside for other less survivable cancers" The Brain Tumour Charity

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"Screening and symptom awareness was one of the most discussed topics within the theme of diagnosing and treating cancer. It was found that people with lived experiences of cancer were heavily involved when discussing how to spot symptoms. One participant who had oesophageal cancer emphasised how important awareness was, given that it is a hard cancer to diagnose." Public consultation engagement event report

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Responses in this area also highlighted areas of the strategy that could be strengthened. This included the importance of adopting a holistic approach to diagnostics and treatment of cancer patients. They identified that the role of General Practice (GP) should be strengthened as the first point of contact for diagnosis. Allied Health Professionals and other specialisms including psychological therapies should be integrated into the strategy and implementation plans. Better access to information and collaboration across primary and secondary care was highlighted, especially GP direct access to diagnostics. There was also a request for the consideration of pre-treatment screening of patients for diabetes.

“The treatment section, specifically radiotherapy is under developed and vague. The document is a complete waste of departmental time and energy if it is not supported by a funding mechanism or pathway to delivery. Effectively it has no teeth and is a lame duck exercise in its current format.” Individual response

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“There is guidance which if implemented, will help to improve the diabetes care of patients in this cohort.[11] Implementation involves screening to identify high risk patients, provision of glucometers, education of patients and early pre-emptive management of hyperglycaemia. We feel implementation will require significant resource and we suggest that this resource requirement needs to be factored into the cancer strategy and funding provided.” BHSCT diabetes, haematology and oncology specialists - Northern Ireland Cancer Centre and Belfast City Hospital

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“We would urge the strategy to include the introduction of specialist MDTs for pancreatic cancer, and other less survivable cancers, so that everyone has access to the best treatment and care.” Pancreatic Cancer UK

Theme 4. Supporting People

As with other areas of the strategy there was broad agreement that the section outlining how people will be supported through their cancer journey was well thought through. There were however some suggestions on how this could be further considered and strengthened. The needs of children and young people, people

facing fertility issues, palliative patients and those with communication difficulties were underlined in a number of responses.

"There needs to be a whole system approach to identifying and providing a comprehensive network of mental health support to people living with cancer. It is critical that a clear and flexible pathway of support is available for people living with cancer to promote their wellbeing and prevent escalation of mental health problems at an early stage. This requires both training and support within services that work with people living with cancer to support awareness of the potential psychological impact of cancer, good early intervention and higher tier specialist interventions."

Macmillan

"Fertility risk from treatment and preservation options should be prioritised. TYAC would like every young person to be offered the opportunity to talk to about their fertility options and how their prognosis may or may not affect that. These conversations should take place regardless of whether the treatment plan involves a treatment that will necessarily affect fertility – in order for young people to have a full understanding of their prognosis and what to expect from their treatment."

Teenagers and Young Adults with Cancer

It was also clear that the role of carers, Multi-Disciplinary Teams and Allied Health Professionals in particular could be better reflected within the strategy.

“Whilst there was a recognition amongst participants on the need for multidisciplinary team working, there was an overwhelmingly strong view on how allied health professionals (AHPs) were portrayed in the strategy. Some AHPs were disappointed at the lack of mention on the work they do in cancer services and agreed there should have been more recognition.” Public Consultation engagement events report

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“A quicker and more clinician to clinician-based service could perform the function of a RDC, ensuring earlier detection rates and supporting GPs as the primary risk holders in patient diagnosis. These must also have robust onward referral mechanisms when pathology identified…Supercharging the General Practice Intelligence Platform (GPiP) could make a significant impact and preliminary work could be quickly adapted to ensure it was available for use.” Individual response

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Theme 5. Implementing the strategy

Throughout the consultation responses received there has been an ongoing theme which identifies the ambitious nature of the strategy, the need for a clear implementation plan and governance arrangements to be established. There was also a significant response in relation to the need for appropriate resources to enable the delivery of this strategy.

“Public and organisational buy-in are essential for the success of the strategy. Also— funding for some innovations and work-force planning will need to be addressed for this to become a reality.

We commend you on this very comprehensive strategy and welcome it for our region.” Marie Curie

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“The strategy can only be implemented with an appropriate cross departmental and cross sectoral implementation team ensuring all aspects of the strategy are implemented simultaneously.” Action on Smoking and Health

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“We would like to see more information about how the strategy will be governed and we can work together to make sure that there is accountability in its delivery – for example by quantifying them and adding timescales for success. Good KPIs and Quality indicators are essential. We also note that some of the issues raised in the body of the strategy, for example the need for financial support, do not get pulled through into the recommendations.” Young Lives Vs Cancer

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“The implementation plan, specific outcome based measures, targets and indeed funding to support the implementation.” Individual response

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"The strategy mentions the involvement of the Community & Voluntary sector which will be integral to the delivery of a successful health service to our communities. However, given the ongoing work of councils and community planning partnerships, in both health and wellbeing programmes and poverty, Councils asks that more collaboration with local government is also considered within this Strategy. Local government should be part of the monitoring and governance of the strategy." Mid Ulster Council

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Responses also identified that a number of key enablers are required to create a sustainable delivery model including; workforce, research and development, access to high quality primary and secondary care data, Information Technology, better partnership working and co-production with service users and carers.

"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." Cancer Research UK

"There is more work to be done in clarifying the plans for different professions… to develop the workforce and training models for CNS, AHPs and psychology is clear

but neither pharmacy or social work are included. Again this is notable especially with respect to SACT and clinical trials as a minimum. Additionally, there is evidence of the gaps in other areas (e.g. palliative care) which would benefit from investment and development of pharmacy workforce.” Northern Health and Social Care Trust

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“There is some concern that there are too many recommendations and that the service will not have capacity to engage in, deliver on and monitor change and reform on this scale. In terms of implementation there is a need to phase and prioritise- many issues will rely on the same small cohort of staff for planning and delivery.” NICAN

“The need to recruit and retain staff again was a constant theme throughout the workshops and to utilise our current workforce and their skills was highlighted, with the need for additional specific expertise required, such as medical physics experts (MPE’s), scientific and technology staffing and radiologists.” Public Consultation event report

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“The development and implementation costs (staffing and associated training and equipment) relating to the use of any new radiotherapy technology or implementation of new treatment techniques need to be included within the core funded part of the service to fully exploit the clinical and cost saving benefits of new technologies.” NICAN

Response to EQIA

Not all stakeholders who responded to the consultation provided a response to the EQIA, however using the information provided by direct answers to the EQIA and Rural needs screening together with relevant answers to other questions a number of significant issues have been identified that will be reflected in the final EQIA, Rural needs and strategy documentation.

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

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

The Rural Needs Act (NI) 2016 screening provides an analysis of how the strategy might affect people living in rural settings in Northern Ireland.

The EQIA and Rural needs screening documents identified a number of issues for people living in Northern Ireland and provided suggested mitigations to ensure ongoing equality of access for the population. The responses received on the EQIA and Rural Needs were supportive of the approach outlined in the documents; they also provided additional suggestions to strengthen the existing commitment to equality particularly in the area of health inequalities and specific requirements to

access services that exist across the equality groups, including gender, age, disability and indeed in relation to the rural dwellers.

It was also clear from consultees that the strategy and its implementation should address the issues surrounding health literacy and communications.

"We welcome that a consultation on the Equality Impact Assessment and Rural Needs Impact Assessment is being carried out concurrently alongside the Strategy consultation. We appreciate the recognition of the importance of the co-production and pre-consultation phase to develop the Strategy, which included workshops with CYPs and the charities that support them, and that during the full consultation period for the EQIA they will continue to be engaged as appropriate. We welcome that the EQIA sets out to ensure a continued focus on monitoring the prevalence of cancer by age and cancer type to support clinically led decision making…. [and] agrees with the ambitions of the EQIA to ensure that the needs of specific groups, including TYAs are considered, as part of plans to improve survival and experience, reduce waiting times, and reduce the impact on both physical and mental health of a diagnosis." Teenage Cancer Trust

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"The paper recognises inequalities in cancer incidence and outcomes in Northern Ireland. However, there is a lack of clarity on the strategic approach to reducing inequalities and the priority actions which might be taken in terms of investment, workforce, research, monitoring or community engagement. With this in mind, we would welcome a strategic commitment to engage a 'Task and Finish' group to

develop recommendations to reduce inequalities in cancer in Northern Ireland to complement the main Strategy.

It is well established that those living with social and economic disadvantage are more likely to experience poorer health outcomes, have reduced access to health care services and have a lower life expectancy and this is also true for cancer patients." Institute of Public Health

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As with all consultation responses the issues raised in response to the EQIA and Rural Needs have been taken into account in the redrafting of the strategy.

Incorporating consultation responses

You Said, We Did

This section of the report will present the changes made to the strategy, these changes are a direct result of the public consultation. The table below will use the "you said, we did" approach to show the correlation between the consultation feedback and the actions taken. Given the breadth and depth of the consultation response this will be a synopsis of feedback received across multiple responses.

Table 1.

You Said	We Did
To achieve the ambitious aims of the strategy a range of key strategic drivers must be put in place.	Reviewed the strategy and strengthened the commitment to establishing key drivers for change to enable the implementation of this strategy, they include: funding, governance, workforce, Information Technology, collaboration and partnership working and data. These issues will also play a significant role in the development of plans to implement the strategy within our services.
Give consideration to language and tone of the strategy	Reviewed the strategy and made a number of amendments to the language and tone used throughout. Changed the title on the infographic on preventable disease.
Reflect the current situation in cancer services, due to COVID-19 and other factors.	Added an additional paragraph has been added to reflect a greater focus on stabilising existing cancer services, supporting and growing the workforce and improving data collection and analysis. Acknowledge that there is learning from COVID-19 and the introduction of positive innovations during a time of crisis.
Better links to existing strategies and plans as well as cross Departmental working.	We have also engaged with the Chief Environmental Officer to consider harmful chemicals and pollutants; and strengthened reference to the Clean Air legislation for NI.

	We have engaged with Chief Medial Officer's office on feedback regarding lung cancer screening. Follow up discussions with departmental colleagues, in Mental Health, Public Health, Health Protection, Primary and Palliative Care and substance abuse. Strengthened section on Making Life Better Strategy.
Direct reference to preventable cancers.	Updated infographic to reflect 2021 data on preventable cancers and changed title. Added a new section on children and young people with a focus on early diagnosis. Reviewed and strengthened references to cancer risk factors.
Greater consideration of Health Inequalities.	Reviewed strategy, moved and strengthened the section on Health Inequalities reflect consultation feedback.
Up to date Cancer information is essential for early diagnosis and treatment.	Added a recommendation to regularly undertake - Pathways to a Cancer Diagnosis report for NI.
Delivery of Bowel screening to a wider age group.	Reviewed strategy and strengthened this section to develop a plan to allow more people to be screened by extending the range.

Greater awareness of psychological treatment and support.	Reviewed strategy and provided more recognition of equitable model of support for patients, this will link with the models outlined in the Mental Health Strategy for Northern Ireland. New recommendation on developing a psycho-oncology framework for NI.
Consider evidence from UK in relation to Screening pilots.	Added sections to consider introduction of a self-sampling pilot for cervical cancer and the development of a pilot for targeted lung cancer screening.
Consider the specific needs of Children and Young people.	Reviewed strategy and strengthened references to children and young people, childhood cancers, early diagnosis and treatment for children and young people with cancer. Reworded recommendation on patient access to staff who are skilled to deliver developmentally appropriate patient centred care. Signposting for carers of children and young people with cancer to charities who can provide information and support.
Give greater recognition to AHP's role in cancer services.	Reviewed strategy and strengthened references to AHP's throughout.

	Added a new recommendation to provide patients with access to appropriate AHP's. Added section on specialist Palliative Care AHP teams.
Provide more detail on the role of radiotherapy.	Reviewed strategy and strengthened section on radiotherapy. Added new recommendations for radiotherapy.
Greater recognition Diabetes.	Reviewed Strategy and added a new section to address the issues raised in relation to Diabetes.
Metastatic disease	We have made a recommendation on the development of regulations on the secondary use of data.
Consider workforce requirements for all specialities.	Reviewed strategy and strengthened references to workforce throughout the document.
Consider the use of technology.	Reviewed strategy and strengthened references to IT and other technology. Added a new recommendation for Telehealth/Telecare.
Provide more detail on how the Strategy will be implemented.	A northern Ireland Cancer Programme Board and supporting governance structures are being established, which will oversee strategy implementation and agreed strategic priorities.

Conclusion

The draft strategy was completed using extensive stakeholder engagement and co-production, which provided a solid basis to shape the development of the strategy and recommendations. The public consultation exercise has enabled the DoH to test the contents of the draft strategy further, it has provided an opportunity for a wide range of stakeholder groups and members of the public to formally share their valuable feedback on the draft strategy. This report is a summary of the all responses received and has attempted to reflect the views expressed during the consultation exercise. It also shows how feedback will be used to strengthen the strategy.

The Department is very thankful for the high levels of dedication, engagement and support received across sectors. The Department is pleased at the overall positive response to the draft cancer strategy and the constructive feedback as a direct result of the ongoing engagement and co-production prior to the consultation.

A revised strategy document will be published in early 2022. It contains 67 recommendations that have been reviewed and revised in line with consultation, resulting in the removal of some original recommendations and the addition of new recommendations. Following publication structures will be established to oversee the implementation of the recommendations outlined in the strategy. Co-production and engagement with stakeholders will central to the delivery of the strategy.

Appendix 1.

	Response to Cancer Strategy Public Consultation
1	TYAC
2	BRCA Link
3	Childrens Cancer Leukaemia Group
4	Southern Trust
5	Mid & East Antrim Council
6	Marie Curie
7	NILGA
8	Royal College of Pathologists
9	Individual response – member of the public
10	Individual response – member of the public
11	Belfast Trust Cancer services involvement group
12	British Association for counselling and psychotherapy
13	Individual response – member of the public
14	NI secondary Breast Cancer
15	Bowel Cancer UK
16	ABPI
17	RCR

18	NI Cancer Registry
19	AbbVie
20	CRUK
21	Royal College of Radiologists
22	Centre for Cancer Research
23	Sinn Fein
24	Jo’s Cervical Cancer Trust
25	Royal College of Nursing
26	Community Pharmacy NI
27	Less Survivable Cancer Taskforce
28	Breast Cancer Now
29	Myeloma UK
30	Better Belfast
31	DAERA
32	Society of Radiographers
33	National Pharmacy Assoc
34	Cancer Focus
35	Beaconbridge Citizenspace response
36	Leukaemia & Lymphoma NI

37	BPS
38	RCPsych NI
39	Asthma UK &British Lung Foundation
40	Clinical Psychology at Royal Belfast Hospital for Sick Children
41	Pink Ladies Cancer Support Group
42	Macmillan
43	Bristol Myers Squibb
44	ICO
45	BDA
46	Institute of Public Health
47	NI Cancer Centre Social Work Submission
48	Newry Mourne & District
49	Radiotherapy workforce project and strategy recommendations
50	South Eastern Local Commissioning Group.
51	Individual response – member of the public
52	Individual response – member of the public
53	Individual response – member of the public
54	Individual response – member of the public
55	Individual response – member of the public

56	Individual response – member of the public
57	Individual response – member of the public
58	Individual response – member of the public
59	Individual response – member of the public
60	Western Health and Social care trust
61	Individual response – member of the public
62	WHSCT North West Cancer Centre
63	Northern Health and Social Care Trust
64	Individual response – member of the public
65	Pancreatic Cancer UK
66	Kyowa Kirin Limited
67	Individual response – member of the public
68	Trinity College Dublin
69	Roche Diagnostics
70	Young Lives Vs Cancer
71	Action Cancer
72	Volunteer Now
73	Individual response – member of the public
74	Individual response – member of the public

75	British Dietetic Association
76	NICaN Pharmacy Group
77	Less Survivable Cancers
78	Individual response – member of the public
79	Skin cancer prevention implementation group - the multi-agency group responsible for implementation of the Dept of Health's current skin cancer prevention strategy
80	Amanda Steele individual
81	NI Cancer Research Consumer Forum
82	Belfast HSC Trust
83	Action on Smoking and Health NI
84	Belfast Trust
85	The Catch Up With Cancer campaign and Action Radiotherapy
86	Beaconbridge Secondary Breast Cancer Group
87	Royal College of Occupational Therapists (with support of the Northern Ireland Regional occupational therapists working in Oncology and Palliative care and RCOT Specialist Section - Major Health Conditions)
88	Teenage Cancer Trust
89	Prostate Cancer UK
90	The Brain Tumour Charity

91	Macmillan Unit, Antrim Area Hospital
92	Teva UK Limited
93	Belfast Trust
94	Northern Ireland Cancer Trials Network
95	Western Health and Social Care Trust - North West Cancer Centre
96	Royal College of Speech & Language Therapists
97	Office of Mental Health champion for NI
98	Southern Health CYP
99	Belfast Trust Cancer Services Involvement group
100	AHPFNI
101	BAMT
102	NICaN AHP Response
103	Southern Trust
104	Individual response – member of the public
105	Speech & Language Therapy - NI Cancer Centre.
106	Royal College of General Practitioners
107	Diabetes - Belfast Health & Social Care Trust
108	Cancer Fund for Children
109	Pharmacy Forum NI

Appendix 2.

Consultation on the Cancer Strategy for Northern Ireland 2021-2031

Feedback from Online Consultation Events

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Background

On 25 August 2021, a draft 10-year Cancer Strategy was launched by the Health Minister, Robin Swann, MLA. The draft strategy 2021-2031 aims to place Northern Ireland at the forefront of world class cancer prevention, treatment and patient experience. The ambition of the strategy is to have a "world class service which is based on improving outcomes for everyone diagnosed with cancer".

Strategy Development

The development of the strategy was led by the Chief Nursing Officer, Professor Charlotte McArdle and was based on co-production methodology which brought together people with lived experience of cancer and healthcare professionals from across all Health and Social Care Trusts (HSC), Public Health Agency (PHA), Health and Social Care Board (HSCB), Primary Care, policy makers and cancer charities.

The draft strategy consists of 67 recommendations drawn from the best available evidence and reflecting the voices of people who use and work in cancer services. The recommendations are across four key themes:

- Reduce the growth in the number of people diagnosed with preventable cancers
- Diagnosis and treatment – to improve survival

• Patient experience – to improve the experience of people diagnosed with cancer

• Implementing the Strategy

Consultation Process

The consultation exercise ran from 25 August 2021 to 20 October 2021. (The EQIA will run until 17 November 2021) and citizens had an opportunity to share their views in a number of ways including:

- Online survey hosted on Citizen Space
- Consultation Questionnaire
- Email or in writing to the Department of Health

Online Consultation Engagement Events

To support direct engagement with citizens, three online consultation engagement events took place on the following dates and times; Tuesday 5 October 2.00 - 3.30pm, Thursday 7 October 11am - 12.30pm and Tuesday 12 October 7.00 - 8.30pm. These events were organised by the Department of Health, advertised through Eventbrite and delivered via the Zoom platform. Sessions were facilitated by the HSC Leadership Centre.

Each session lasted approximately 1.5 hours and over the three workshops, a total of 145 people attended, including representatives from; HSC Organisations, Charities, the Voluntary and Community sector, Education, Pharmaceutical Organisations,

The online engagement events included:

- Strategy overview, principles and timeline delivered by the Chief Nursing Officer;
- Overview of the key themes, context and recommendations from the Cancer Strategy co-chairs, plus members of the Strategy subgroups;
- Overview of implementation by representatives from the Department of Health

The engagement exercise focused on the key themes and recommendations. The discussion was led and facilitated by the workshop contributors and in smaller breakout rooms of approximately 15, attendees had an opportunity to share their views and suggestions. These findings were captured by scribes and key points shared by the facilitators during each workshop.

The information contained within this report will cover the responses to the main points raised over the course of the three online events. Other topics of conversation are prevalent throughout the findings, but it must be emphasised that the report is evidence of how participants responded to the key themes set out in the strategy.

Acknowledgement

The Department of Health would like to acknowledge everyone that participated in the online engagement events. There was a good level of engagement and participation throughout the events, with personal insights being shared over the sessions.

Theme 1 Preventing Cancer

Following the context setting and sharing of key recommendations, participants were asked the following questions:

1. Do you agree with the recommendations?
2. Any other comments?

The overall consensus coming from the workshops is that people strongly agree with the contents and recommendations set out in the draft 10-year strategy.

The key themes discussed under Prevention include:

- Education must be a priority in preventing cancer. Participants stressed the usefulness of incorporating cancer education and raising awareness into the schooling systems from primary schools/early years and above. This followed with targeting groups that have a higher chance of suffering from certain cancers. For example, girls' schools learning about breast cancer awareness. Additionally, working in partnership with the Education Authority to advance this suggestion was raised.

- It was highlighted that many people do not fully understand dietetics. Some participants felt as though food labelling was inadequate and that there isn't a clear difference between healthy and unhealthy options. It was pointed out that a high

volume of food outlets are selling unhealthy foods, whilst being more readily available due to lower costs.

- There was an acknowledgement of the strong link to cancer rates and health inequality, and it was recognised and agreed that healthy options are not always affordable in deprived areas.

- The need for ongoing and concentrated prevention of smoking was raised throughout the events with one participant suggesting that cancers rates should be are displayed on tobacco products as it might encourage users to stop smoking.

- The need for “stronger” language around existing strategies was recommended as was the need for performance management, accountability, target setting and greater co-ordination across sectors.

- A need for accurate, timely and accessible data to inform and manage decisions was raised, and it was recognised that that this will enable a greater focus on those “targeted” for additional surveillance so that an early diagnosis of cancer can be made.

- We must be cognisant of any positives lessons learned during the Covid-19 pandemic and specifically the increased use in digital medicine and how this could potentially streamline some of our waiting lists and processes, and also the importance of new medication being trialled.

- Whilst it was acknowledged that ongoing awareness and prevention campaigns are all positive, it was recognised that as a society we need to do more to take responsibility for a change in our own behaviour, lifestyle and preventive measures including diet and exercise.

- The blind, deaf and non-English speaking communities were also mentioned when considering how they can access awareness campaigns. As well as how prevention of cancer in children is addressed, given that most childhood cancer cases are not due to lifestyle choices.

- There was positive recognition for the inclusion of blood cancers within the Cancer Strategy.

- Primary and secondary care provision was raised, with some suggesting there should be a greater focus on diagnosis at a primary care level and that this could be an opportunity to redesign services so that they could be delivered in the community akin with some of the English delivery models.

- Overall, the consultation heard that educating and raising awareness for preventing cancer can be praised, however several participants made note to the fact that doing so may result in the perception of 'blame culture' and so this needs to be approached carefully and tactfully when implementing the recommendations.

- Participants acknowledged the presence of health inequalities within the strategy. One participant mentioned the idea that understanding prevention of cancer is not a top priority in these areas, with residents more concerned at rising energy and food bills. This followed with the question on how to reach these communities to persuade them to change? Further reiterated by one participant who stated they did not know the link between alcohol and obesity contributing to breast cancer, explaining that more communication about cancer is needed in areas of deprivation.

- The need for ongoing community development is required to support the prevention messages, as well as empowering and supporting people to make better choices. Furthermore, some echoed the concern over unhealthy lifestyle choices when it came to food, stating that children should be encouraged to take interest in healthy cooking and nutrition from a young age.

- The importance of messaging was discussed and the need to engage with different communities and target groups must be reinforced so that the message reaches them directly.

- Participants who worked in cancer related charities also stressed the importance of community and voluntary collaboration. With this, they were pleased to see prevention being pushed, particularly with skin cancer and smoking strategies being aligned. They did suggest however, a need for stronger language, which is time specific. This reflects comments from a panel member explaining that government

statistics show sunbed and vaping shops have a much higher incidence in deprived areas.

- Other comments around prevention were provided by those working in or with local councils and authorities. With a background in health promotion, one participant stated that working with councils and implementing prevention strategies lead to a drop in the number of sunbed shops in those areas. Another participant working in a local authority told of how they were heavily involved in prevention when it came to air pollution. However, they felt as though no action was taken towards this concern. This could be due to Northern Ireland currently not having a dedicated strategy to reduce air pollution (p. 25).

Theme 2 Diagnosing and Treating Cancer

Following the context setting and sharing of key recommendations, participants were asked the following questions:

1. Do you agree with the recommendations?
2. Any other comments?

The overall consensus coming from the workshops is that people strongly agree with the contents and recommendations set out in the draft 10-year strategy.

- Screening and symptom awareness was one of the most discussed topics within the theme of diagnosing and treating cancer. It was found that people with lived experiences of cancer were heavily involved when discussing how to spot symptoms. One participant who had oesophageal cancer emphasised how important awareness was, given that it is a hard cancer to diagnose.

- It was also highlighted that people living with Barrett's Oesophagus require screening as they are more at risk of developing cancer. In relation to this point, others were eager to see Cytosponge screening being used in Northern Ireland in the future. This reinforces a strong emphasis on widening the boundaries on screening services in order for earlier detection.

- The idea of expanding the use of lung screening services for younger people was raised, particularly for men in the construction industry who are exposed to chemicals. One participant explained that five of their family members have suffered with lung cancer from working in the construction industry and not due to smoking.

- Moreover, a participant living with bowel cancer stressed that there is a fine line between scaring people with awareness and not giving enough information due to COVID. Again, it was pointed out that ovarian cancer is hard to diagnose and there are inadequate screening services for this.

- It was also requested that when screening services are designed, they need to be accessible for blind and partially sighted people.

- Overall, early detection was emphasised over comments that presentation of cancer isn't always clear, especially with vague symptoms.

- The concept of diagnostic hubs was welcomed, particularly as those in Wales and Scotland are focused on patients with vague and worrying symptoms. An elderly participant living in a rural area explained that it is often difficult to get to major hospitals and stressed how important the availability of diagnostic hubs would be.

- However, some in the workshops struggled to see the development of the treatment hubs taking place in Northern Ireland. It was unclear to some participants what would be included in the hubs and how resources would be used efficiently, based on their

use elsewhere in the UK. For example, would there be access to diagnosing rare and less common cancers?

- Participants were largely positive about the hubs, however, for some it was seen as ‘ambitious’ within a 10 year timescale. It was also mentioned that in England, a fine is incurred if diagnosis exceeds its target and whether the same idea would be implemented in Northern Ireland.

- A few participants were happy to see the 28 day target when referring to pancreatic cancer. Others said that it needed to be a shorter timescale and that 28 days was too long for aggressive cancers, making them untreatable.

- It was mentioned that biopsy results can take up to five weeks for the majority of patients. A HSC staff member stated that this goal would be ‘really difficult’ in the current context due to lack of resources.

- It was agreed amongst many that there is a need for more staff in order to achieve the goals set out in the strategy, and this need ran throughout all the sessions and was highlighted under each of the three themes.

- The need to recruit and retain staff again was a constant theme throughout the workshops. (At this stage, the CNO advised that the Minister has commenced a workforce review of cancer services, which will report back over the coming months).

- The need to utilise our current workforce and their skills was highlighted, with the need for additional specific expertise required, such as medical physics experts (MPE's), scientific and technology staffing and radiologists.

- Whilst there was a recognition amongst participants on the need for multidisciplinary team working, there was an overwhelmingly strong view on how allied health professionals (AHPs) were portrayed in the strategy. Some AHPs were disappointed at the lack of mention on the work they do in cancer services and agreed there should have been more recognition.

- Concern over the lack of GP appointments was also shared, given that this can cause delays in diagnosis. Some participants felt that members of the public are hesitant to attend GP surgeries, therefore it was recommended that, GP services need to be equipped to have appointments available in order to follow the correct diagnosis pathway.

- Participants also highlighted the need for new equipment and technologies when diagnosing and treating cancer, such as MRI scanners, camera capsules and proton beam therapy.

- The lack of access to clinical trials in Northern Ireland was also highlighted, given that there were no recommendations on how these will be improved. Furthermore, a participant expressed their frustration at how patients currently have to travel to England for these trials. Similarly, the strategy did not cover access to cancer treating

drugs and left some questioning why it takes longer to get drugs approved in Northern Ireland than in England.

Theme 3: Supporting People

Following the context setting and sharing of key recommendations, participants were asked the following questions:

1. Do you agree with the recommendations?
2. Any other comments?

The overall consensus coming from the workshops is that people agree with the contents and recommendations contained under Theme 3; Supporting People in the draft 10-year strategy.

- Most participants who touched on this point agreed having access to a Clinical Nurse Specialists was positive. However, comments suggested that there is still work to do in this area.

- Again as in previous sessions, the importance of recruiting and retaining cancer specific workforces must be addressed. This was followed by a suggestion that there is a need for advanced communication training amongst these professionals.

- A participant with lived experience of cancer shared their story about the lack of support they received whilst waiting for results from an X-ray. They explained that people need support at every stage of their diagnosis, with a panel member agreeing

this would have been in the form of a CNS. Therefore, they must be continually invested in in order for cancer patients to receive the highest quality of support and care.

- Participants responded well to the inclusion of the holistic needs assessment in the strategy. However it was suggested that the use of language could be improved, specifically with a change in narrative. For instance, 'supportive care' was recommended in order to engage people more.

- The point that palliative care is identified and introduced early was welcomed, reflecting points made in page 86 of the strategy. Others emphasised that the '*Living Matters, Dying Matters a Palliative and End of Life Care Strategy for Northern Ireland'* is over 10 years old and there is a perception that little has changed since this was published.

- Another participant recalled patients with cancer diagnoses being moved straight to end of life care, when palliative care should have been a possibility. Moreover, it was stated that services are dependent on Trust geographical areas regarding and there is no equality in how these services are accessed in Northern Ireland.

- Participants with lived experience of cancer discussed the way in which diagnosis is delivered. It was agreed that cancer support skills are specialist and that staff need trained appropriately. One participant described the deliverance of diagnosis, 'at the

mercy of the consultant's personality.' It was added that there is lack of uniformity when staff deliver upsetting news and that there should be training for this.

- Additionally, medical terminology makes diagnosis more difficult for the patient to understand and regular hospital visits that follow may not be with the same consultant.

- There was a sense that those who had been through these experiences wanted more of a personal service, with some stating they felt they needed more support when accessing cancer treatment as in many cases support is offered when treatment has finished.

- Need for ongoing psychological support was reiterated through the sessions.

- It was recognised that there is a heavy reliance on charities to provide support for people living with cancer. Some participants felt as though they were relied on to 'pick up the slack'. For example, Cancer Focus NI working with patients who felt at loss once treated, whilst previously speaking highly of the health service.

- Representatives from the Cancer Charities emphasised how important their support work is, particularly for people's mental health, adding that it is often affected by timelines given at diagnosis.

- One participant said “I'd like to take the opportunity to thank the health services. I had a cancer scare a few years ago; at blood sugar check my blood sugars were 28... I was passed on to my GP who was on site; consultant app; diabetic nurse checked with me daily for 3 weeks and after medical intervention, suffice to say all is well. A wonderful service to me”.

- The need for funding was continuously raised, with participants stressing that more resources needs to go into health services for staff to provide the necessary support.

- There was some differing feedback on participant experiences with support provided. One participant had observed the difference in care between Northern Ireland and England, stating that in England they were encouraged to ‘co-own’ their treatment plan and understand what happens rather than it being ‘done’ to them. They went on to say that consultants in Northern Ireland were looked upon so highly, that most people take what they say as true when they don’t always know best. This may be an isolated case; however it is important that all people affected by cancer receive appropriate care and support and it should be considered whether Northern Ireland can take inspiration from working styles used in other parts of the UK.

- A prevalent topic running through all the workshops was data collection. Initially, participants questioned the use of data in the strategy and why there wasn’t a focus on why cancer is occurring. They suggested using data modelling and clinical research, similar to that used with COVID, to understand patterns and insights further.

- Others felt that the Cancer Patient Experience Survey (CPES) wasn’t designed inclusively. For example, there was no mention of CPES for children and young people, something that has been established in England via PICKER institute. This followed with the question of how the results of the survey would be reviewed every 2 years and how would changes be implemented.

- There was also disappointment at the lack of mention around metastatic cancer and whether more research would be conducted towards this, given it is mandatory in England.

Theme 4 Implementation

The final theme of the workshop was an overview of the strategy Implementation, which includes:

- The development of a NI Cancer Programme Board to oversee the delivery of the strategy;
- The need for a robust suite of regional key performance indicators to monitor the implementation of the strategy as part of ongoing evaluation arrangements. In addition consideration will be given to linking funding to the delivery of outcomes and achievement of KPI's;
- NI Cancer Programme Board, with strong clinical leadership, will be established which will include people with lived experience of cancer;
- Delivery at this scale and speed will require investment in planning and project support infrastructures both within Trusts and across Clinical Networks, in particular The Northern Ireland Cancer Network (NICaN);
- Creating a sustainable workforce to care for those with a cancer diagnosis must be an integral part of the Cancer Strategy;
- Optimum use of data;
- A restructure of the NI Cancer Network and ensure it is supported and resourced to implement the strategy and to deliver a world class cancer service;

- Development and implementation of a regional multi-professional workforce plan aligned to a regional approach to training;
- Undertake a Cancer Patient Experience Survey every 2 years;
- Development of a robust research function.

Conclusion

Whilst the strategy has set out 67 high-level recommendations, particular recommendations were brought forward to share in the consultations. Audiences included the general public, health care professionals, the voluntary sector and many more, each with different perceptions of cancer and how they are affected by it.

This report displays the main points of discussion across all three consultations, with all feedback from participants seen as important and valuable. Upon reflection, it shows strong participant interaction, with little hesitation when it came to recommending further, as well as critiques.

Collectively, the key themes being shared from the consultation exercise include;

- Importance of co-production in the implementation stage of the strategy
- Funding and how it can be identified to support the implementation
- Co-ordinated approached. No one Agency or Department can achieve the recommendations contained in the Strategy, so it must be a collective approach with a strong focus on community development
- Focus on prevention and specifically education and how we get across key messages relating to prevention, especially, smoking and obesity and their correlation with cancer rates

- Focus on workforce, and the need to not only recruit but retain our cancer workforce, and those identified as having specialist roles.
- More effective links between primary and secondary care providers
- Health inequalities and links to cancer must be have a combined approach with Policy driving behaviour
- Data and measurements are imperative

In summing up, perhaps one of the biggest challenges identified was doubt on whether the strategy could be implemented in 10 years and how much would actually be achieved during this time, given the added stress of the pandemic and our current workforce challenges.

However, the findings of this report have demonstrated positive participant feedback, with many choosing to share their personal experiences of cancer, and this is demonstrated in some of the testimonials from participants including:

“Thanks for the opportunity this was a very useful, and insightful, which allowed input from many different people. I really enjoyed the format and delivery of the information in bite size pieces to allow full discussion on each section. Everyone views this differently which is useful, and provides a more rounded understanding. The main issues will be funding and staffing. It is evident there has been a lot of work. Thank you”

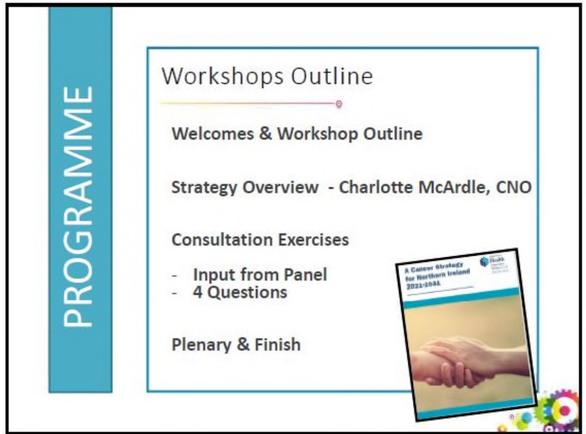
Next Steps

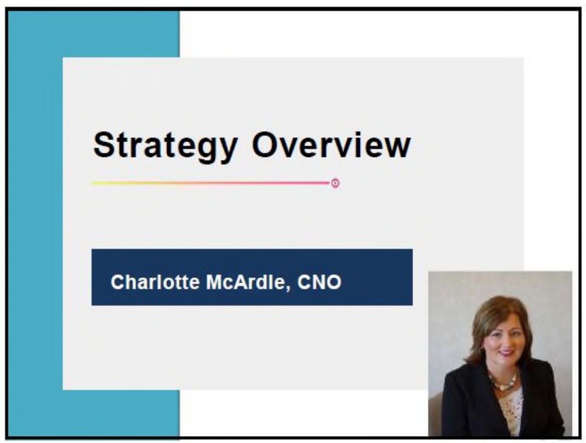
The findings from the online engagement events will now be shared with the Department of Health and will inform the findings of their overall consultation exercise.

References

2021. *A Cancer Strategy for Northern Ireland 2021-2031*. [pdf] Department of Health, pp.20, 25, 84, 112. Available at: <https://www.health-ni.gov.uk/sites/default/files/consultations/health/doh-cancer-strategy-2021-2031.PDF> [Accessed 26 October 2021].

Appendix 1 – Consultation Presentation





Panel Members

- Heather Monteverde, Department of Health
- Paul Cavanagh, HSCB
- MaryJo Thompson, South Eastern Trust
- Alastair Campbell, Department of Health

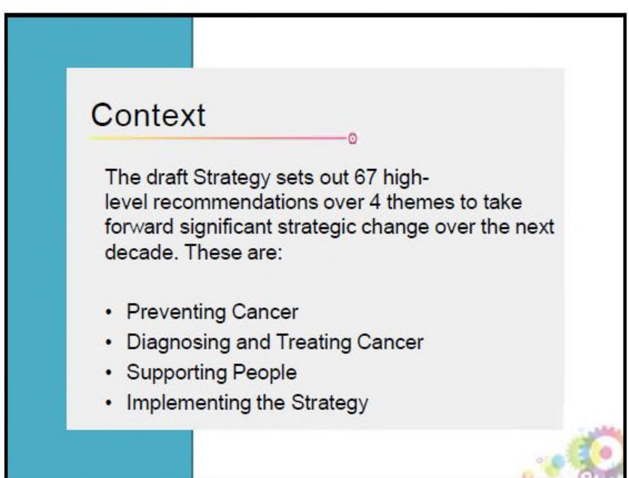
Timeline

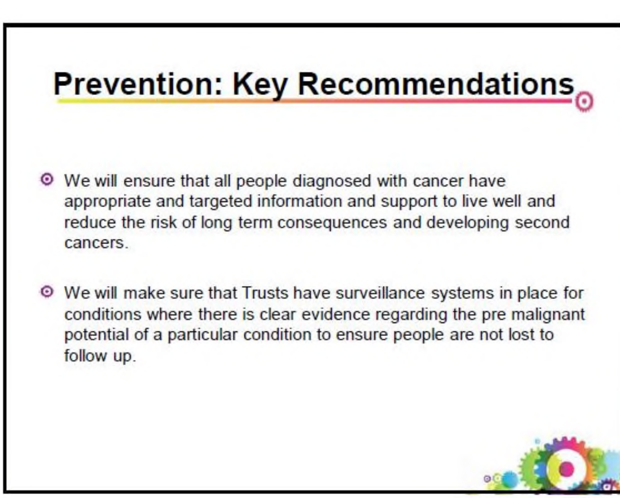
- The Strategy development commenced in May 2019 but was very significantly impacted by COVID-19
- The consultation will run from 25 August 2021 to 20 October 2021, the EQIA will be consulted on for an additional four weeks until 17 November 2021.

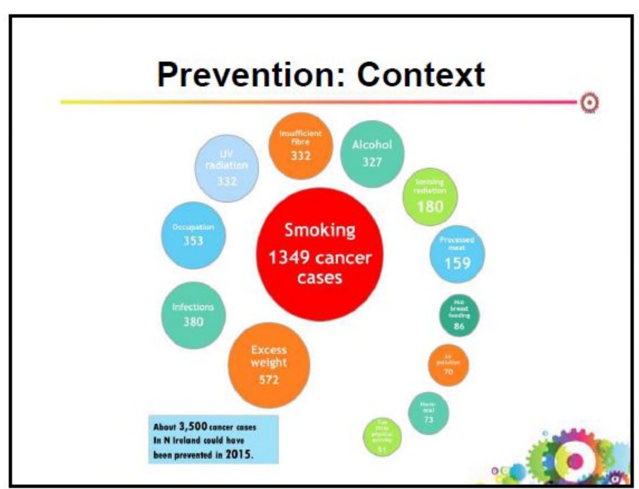
Prevention: Key Recommendations

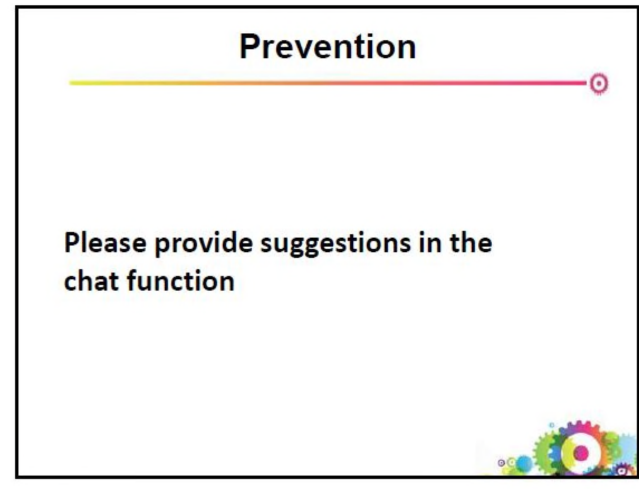
Support the implementation and the future development of:

- Tobacco Control Strategy
- Obesity Strategy
- Skin cancer prevention Strategy
- Substance Abuse Strategy
- We will liaise with the Department of Agriculture, Environment and Rural Affairs and support the development and delivery of Northern Ireland's first Clean Air Strategy.









Diagnosing and Treating Cancer: Context

- A new approach is required to improve the diagnostic pathways in NI. If change is not made, waiting times will continue to deteriorate

Diagnosing and Treating Cancer - Questions

Please provide suggestions in the chat function

Diagnosing and Treating Cancer Key Recommendations

- 'Be Cancer Aware' campaigns.
- Increase uptake of all cancer screening programmes, particularly in seldom heard communities.
- People who have cancer are diagnosed as quickly as possible
- Adequate staffing, infrastructure and equipment in place
- Development of diagnostic hubs.
- 28-day diagnosis standard from first referral for suspected cancer to confirmation of a cancer diagnosis and includes all diagnostic and staging investigations
- We will develop and implement prehabilitation and rehabilitation services on a regional basis for all those who will benefit.
- We will develop near to home phlebotomy services by 2023

Supporting People – Context

- Person centred approach to cancer care
- The Recovery Package when delivered together, greatly improves outcomes for people living with and beyond cancer
- Research indicates that 21% of people living with cancer experience mental health problems
- Benefits advice services, financial guidance and hardship grants for patients are a vital means of supporting people facing the financial hardships caused by cancer.
- Provision of Advanced Communication Training for all HCPs

Diagnosing and Treating Cancer Key Recommendations

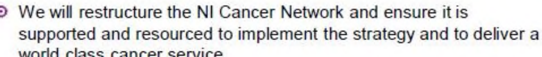
- Person centred model of care
  - effective and efficient,
  - built on learning from COVID 19
  - increasing use of telehealth and technology
- Appropriate pathways and services for older people with cancer, rarer cancers, teenage and young adults and people seldom heard.
- All people, including children and young adults, are cared for in an environment appropriate to their needs
- Multi-Disciplinary Team meeting for all people diagnosed with cancer including cancer of unknown primary and metastatic disease
- Gain access to clinical trials for as many people as possible; including children and young people
- We will develop ambulatory care haematology units within each of the five Trusts and establish near to home treatment services for suitable patients

Supporting People: Key Recommendations

- We will ensure that all patients, including children and young people, diagnosed with cancer have access to a Clinical Nurse Specialist throughout the entire care pathway.
- We will make certain that all those with a cancer diagnosis are referred to a Cancer Information and Support Service at diagnosis and advised of the range of services available across their entire cancer pathway.
- We will make sure that all people are offered a holistic needs assessment, an appropriate care plan is developed and they are signposted to relevant sources of help and support.
- We will develop a comprehensive treatment summary record for all people diagnosed with cancer. On completion of their treatment, this will be provided to them and their GP.

Supporting People: Key Recommendations

- We will make sure that all people with cancer have equitable access to psychological support which is tailored and specific to their needs
- We will make sure that all people are assessed and risk stratified to appropriate, high quality, follow-up pathways on completion of treatment.
- We will arrange a palliative care keyworker for all people with non-curative cancer when required.
- We will arrange equitable access to palliative and end of life support and continuity of care for all people with non-curative cancer 24 /7



Implementation – Key Recommendations

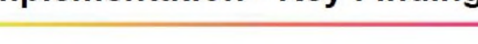
- We will restructure the NI Cancer Network and ensure it is supported and resourced to implement the strategy and to deliver a world class cancer service
- We will develop and implement a regional multi-professional workforce plan aligned to a regional approach to training
- We will undertake a Cancer Patient Experience Survey every 2 years
- We will develop a robust research function

Supporting People – Questions

Please provide details for your answer on the chat

Additional Comments

- Is there any additional information you feel is relevant to this consultation?
- We are particularly interested in responses that relate (but not limited) to the EQIA and Rural Needs elements of this consultation.



Implementation - Key Findings

- NI Cancer Programme Board, with strong clinical leadership, will be established which will include people with lived experience of cancer.
- Delivery at this scale and speed will require investment in planning and project support infrastructures both within Trusts and across Clinical Networks, in particular The Northern Ireland Cancer Network (NICaN).
- Creating a sustainable workforce to care for those with a cancer diagnosis must be an integral part of the Cancer Strategy.
- Optimum use of data

Ways to Respond

Online:
Consultation on the Cancer Strategy for Northern Ireland 2021-2031 - NI Direct - Citizen Space

Email:
Cancer.Strategy.2020@health-ni.gov.uk

Write To:
Cancer Strategy Project, Department of Health
Room 1, Annex 1, Castle Buildings, Stormont Estate
Belfast, BT4 3SQ

Appendix 2 – Online Engagement Project Group

Engagement Project Team

- Heather Monteverde, Department of Health
- Paul Cavanagh, Health and Social Care Board
- MaryJo Thompson, South Eastern Trust
- Alastair Campbell, Department of Health
- Gay Ireland, Department of Health
- Mary Boyle, Facilitator, HSC Leadership Centre
- Roisin Kelly, Event Lead, Department of Health

Scribes

- David Cassidy, Patient Client Council,
- Emily Docherty, HSC Leadership Centre
- Gina Biggerstaff, Department of Health,
- Anne Marie Doon, Patient Client Council