A Cancer Strategy for Northern Ireland 2021-2031

Department of Health
An Roinn Sláinte
Männystrie O Poustie
www.health-ni.gov.uk

Cancer Strategy 2021-2031

Consultation Document

Annex B: Consultation Response Form

I am responding:

(please tick one option)

As an individual _____

As a health and social care professional _____

On behalf of an organisation _____**X**_____

About you or your organisation:

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If replying as an individual, please indicate if you do not wish for your identity to be made public.

Consultation Questions

Number	Question
Strategic priorities	
1	Do you agree that the strategy has identified the correct strategic priorities? Yes Do you have any further comments? **About Cancer Focus Northern Ireland:** **Our Vision** - A future where cancer is a manageable disease. **Our Mission** - To eliminate cancer where possible and reduce its impact on society. **Background** Cancer Focus Northern Ireland wants cancer incidence rates here to be among the lowest in the world: we want our cancer patients to have among the best outcomes in the world. This is ambitious, but we believe our people deserve nothing less.

	In 2019 Cancer Focus NI celebrated 50 years working to reduce the impact of cancer on local people's lives. We provide care and support services for cancer patients and their families; offer a range of cancer prevention programmes to help people reduce their risk of getting cancer; fund scientific research into the causes and treatment of the disease and campaign for better health policy to protect and empower our community and its future. **Strategic Priorities:** Cancer Focus NI campaigned for many years for the new Cancer Strategy, supported its development through our work on sub-groups and facilitated engagement with MLAs and other stakeholders via providing the Secretariat to the Assembly's All-Party Group on Cancer (APGC). Therefore, Cancer Focus NI is delighted to engage during this important consultation process. We are confident that a properly resourced and implemented Cancer Strategy will address the needs of local people and can be central to rebuilding our health and social care system. Cancer Focus NI welcomes the co-production approach taken in the Strategy's development, and we are delighted to see the focus on patient-centred care at its heart. By highlighting the enormous potential for cancer prevention, and in particular, the necessity to tackle health inequality, the strategy is validating Cancer Focus NI's long-term vision and mission. The document is well laid out and subdivided into prevention, diagnostics and treatment, Supporting People to live well and die well implementing the strategy. It is well backed up with current data, chiefly from the Cancer Registry. Collaborative working with elsewhere in the UK and Republic of Ireland--is laudable--especially for the rare, often children's cancers. It is encouraging to see prevention identified as a key strategic priority. The cost effectiveness of preventing cancer vastly outweighs that of treating the disease. Therefore, commitment must be shown towards long term objectives and significantly enhanced, and clearly structured cross departmental arrangements set up on cross cutting thematic areas. In addressing cancer risks from smoking, alcohol and obesity it must be

	made clear that these are also significant risk factors in many other NCDs and thus gain real buy in to the strategy from a wider range of stakeholders across more sectors. Treating the emotional impacts of cancer on patients, families and carers needs much more emphasis. **Role of the Community and Voluntary Sector** The role of the community/voluntary sector has not been adequately recognised in terms of the volume and complexity of work carried out in this area and there is no clear commitment to adequately resource this in future. Cancer Focus NI advocates a regional Psycho oncology framework established to allow for effective referral pathways alongside the stepped care model. This strategy is an important opportunity to embed the emotional and psychological needs of people within the cancer system. It must not be missed.
Theme 1: Prevention	
2	Do you agree that these recommendations will reduce the number of preventable cancers in NI? Yes Do you have any further comments? The recognition of the enormous potential for cancer prevention is very welcome. We would, however, add the following important comment; **<u>Integration with existing and new strategies</u>** The inclusion of the European Code Against Cancer is very welcome. However, when the draft Strategy refers to smoking, UV radiation, obesity, nutrition, physical activity and alcohol the vocabulary used is very weak: “We will take account of the learning and progress made through the implementation of the …*smoking/obesity/skin/substance abuse*……. strategy”. Many of these existing strategies are coming to the end of their current lifespan and work should have already begun on developing long term well-resourced ambitious new strategies that will, for example, aim for a tobacco free society, addressing inequalities and novel nicotine delivery systems.

As the draft Strategy acknowledges that ambitions of achieving a 'smoke free' target of 5% average adult smoking prevalence have been set in some UK nations but, to date, not in Northern Ireland. This inertia and lack of vision has been translated into poor public policy with Northern Ireland lagging behind neighbouring jurisdictions. For example, we've only recently had a commitment to implement a ban on smoking in cars carrying young people and there is an urgent need for a smoke-free prisons policy.

In addition, the difference in lung cancer incidence across social groups is largely due to the noticeably higher smoking prevalence in the most deprived areas (27%) than in the least deprived (10%). Cancer Focus NI have long advocated for a targeted approach prioritising interventions in the most deprived and 'at risk' settings and communities where incidence is highest.

Health Inequalities

The focus on reducing health inequalities is very important and is welcomed. The huge influences of equalities on health outcomes are stark and are highlighted in Cancer Registry data. Cancer incidence in general is 14% higher than average in the most deprived areas. There is an even stronger link between for example lung Cancer and deprivation

Cancer incidences and survival rates are influenced by complex interactions of many social, economic and lifestyle factors. Hence the necessity for strong healthy public policy supported by clearly structured cross departmental implementation processes.

Health Inequalities are highlighted as a priority- marginalised communities (including BAME) are listed - members of the Travelling Community and the LGBTQ+ community face significantly poorer outcomes and health inequalities. People can also be members of multiple marginalised communities facing multiple barriers when accessing healthcare/poorer health outcomes as a result.

<u>Implementation of Public Health Policies</u>

Again, the wording used is far too weak: "We will raise public awareness of the links between …. and cancer".

Raising awareness alone will not have a significant impact on prevention. We require more comprehensive policies and strategies that empower people, communities, and at-risk groups to assimilate this increased awareness into sustained behaviour change and to create healthier communities.

	This can be achieved by comprehensive public health policies being integrated into all policies across every department of government and their agencies. Cancer Focus NI co-authored and launched the UK's Independent **Alcohol Strategy** "Health First" at Stormont in 2013. Yet we still await Assembly legislation on our 10 recommendations. Neighbouring jurisdictions have already legislated in these areas e.g., Minimum unit pricing. We welcome the inclusion of Oral Health and references to Head and Neck cancers. Likewise, we welcome the inclusion of a sections on UV radiation, Nutrition and Physical Activity, Environmental pollution, and radon. We welcome the recommendation that a new skin cancer strategy should include a specific focus on **occupational skin cancer**. On page 21 "We will raise public awareness of the links between skin cancer and cancer" should read: "We will raise public awareness of the links between UV radiation and cancer" The section on **radon** is very short and does not give any specific information on NI. This may be because raw data for indoor air radon concentrations in NI are held by Public Health England, and not by the NI Environment Agency, or the Geological Survey of Northern Ireland. This situation is problematic, as without access to the raw data neither NI based organisation can gain a full understanding of the negative health effects that radon has on the general population in NI. It is very telling that the consultation document cites the number of radon related deaths from radon exposure for the UK, but not specifically for NI. It is clear such health statistics are currently unknown for NI. This situation should be rectified as a matter of priority
Theme 2: Diagnosis and Treatment	

3	Do you agree that these recommendations will improve outcomes for people living with cancer? Yes Do you have any further comments? We have a number of comments to make in this section. Firstly, we welcome the relaunch of the PHA's "Be Cancer Aware" programme and as previously, our experienced Cancer Prevention team are willing and able to support its roll out. The comparative survival figures provided for diagnosis during screening vs ED presentation should be promoted widely along with awareness raising of signs and symptoms especially given the numbers of undiagnosed cancers due to Covid. Lung cancer screening will bring great improvements. We advocate; a full implementation of the UK National Screening Committee 2016 Recommendations as a priority to address the difference in access between women living in Great Britain and Northern Ireland. Commencement of the delivery of HPV Primary Screening in an earlier and specific time frame. Currently the switch to HPV primary Screening from cytology has been "agreed in principle" and the implementation date is vague - in 2022/2023 The establishment of diagnostic hubs should be prioritised along with associated funding requests. We welcome funding to pilot projects that offer insights into prehabilitation and how community based / charitable organisations may be best placed to offer this service. Early diagnosis will lead to better outcomes for many. However, our **waiting times targets** have not been met and would require genuine transformation to achieve meaningful benefits. Having led the "Equal access to cancer treatments" campaign Cancer Focus NI is determined that local people are provide the same standards as in GB.
Theme 3: Supporting People	

4	Do you agree that these recommendations will deliver person centred care? Yes Do you have any further comments? **Dedicated CNS** We support having patients supported by a clinical cancer nurse throughout their cancer journey and not just diagnostic and surgical element of treatment. A dedicated CNS can also signpost to other services that can assist recovery and would provide patient centred support in a very complex system. **Psychological support** Cancer Focus NI endorses the strategy's view that "recognising and treating distress in people living with cancer must be a priority", and we welcome the inclusion of the need for appropriate and timely psychological support for people impacted by cancer. **Counselling and psychotherapy** We would like to see much greater recognition of the role of counselling and psychotherapy in the strategy document, and in particular the widespread contribution of third sector counselling provision in the emotional and psychological treatment of cancer-related distress, as well as the absence of a standardized funding model. The strategy should more robustly reflect the volume and complexity of the work that counsellors and psychotherapists contribute to the field of cancer care. We believe that the treatment of the emotional and psychological impacts of cancer should be considered as integral as the physical treatments in terms of people's quality of life. **Service user feedback and the role of the Voluntary Sector** Our experienced staff provide a much-needed range of support services to cancer patients and their families. The public have long recognised the value of these services. For example: "*This service was so helpful to me and put closure to my diagnosis. I see a new beginning and put all my worries, demons behind me. Someone listened! I'm so grateful and thankful for this service. Every bit important to me as my operation and treatment was to cancer*." Pg86: "Counselling supports people dealing with the emotional impacts of cancer. Whilst there is an array of services available across health and social care and in the community and voluntary

sector awareness of services and access to services remains a challenge for many."

Resourcing of counselling and psychotherapy services

In 2019 Cancer Focus NI offered 4905 counselling appointments to cancer patients, families, and those bereaved by cancer. In 2020 we offered 3303 counselling appointments despite the necessity of furloughing staff due to Covid-19 and reducing our capacity by 66%. The lack of a regionalised approach to statutory funding for counselling in general and the cancer sector in particular means that third sector organisations carry the financial burden of providing this vital service across NI.

The impact of Covid 19 on the voluntary sector has exposed the vulnerability of these vital services. We are strongly of the view that the challenge to clients is not awareness of services, as evidenced by long waiting lists, but the lack of ability to adequately staff and plan services due to a lack of financial security.

The strategy should clearly recognise the barrier to access that is caused by the insecure funding landscape and commit to the **adequate resourcing of counselling and psychotherapy** delivered by the third sector.

The status of counselling

Pg89: "Therapeutic services is an umbrella term which represents a wide range of support services. This includes complementary therapies, counselling..."
Counsellors are working continually with people right throughout their cancer journey, from diagnosis to death, and with the impact and aftermath of this on families and carers. They work with trauma, anxiety, fear and grief to name just some issues. They are faced with the loss of clients and the grief this entails. They are qualified and accredited professionals with years of training and hundreds if not thousands of clinical practice hours who work alongside other Allied Health Professionals in cancer care and liaise closely with Clinical Nurse Specialists, Consultants, GPS and others.
We call for the status and professionalism of counsellors and psychotherapists to be recognised within the strategy document and that counselling is included alongside Psychology under Psychological Support rather than alongside Step 1 interventions under the umbrella of Therapeutic Services. We believe that counselling practitioners more naturally align with this type of psychological support as opposed to complementary therapies.

Pg110: "Psychology services are vastly oversubscribed with waiting lists across NI. A new model of service provision is required to

	ensure that all those who need psychological support have access to appropriate services." Our Counsellors in Cancer Focus NI work closely with Psychology in a number of Health Trusts. The numbers of referrals to counselling within the third sector are as oversubscribed as those of Psychology, however with no equivalent statutory support. Counsellors working within the third sector are often expected to take over from Psychology when waiting lists are closed or are referred cases which should stay with Psychology due to their complexity. We call for this statement to reflect "psychological services are vastly oversubscribed..." to include counselling and psychotherapy as mentioned above. **Regional Psycho-oncology Framework** During the sub-group stage of the development of the strategy document Cancer Focus NI called for the development of a regional Psycho-oncology Framework to identify best practice and clear referral pathways, with the long-term aim of establishing a Regional Psycho-oncology Service. This would allow for timely and appropriate access to emotional and psychological support for those impacted by cancer throughout the cancer journey following the stepped care model. This recommendation was omitted from the strategy. We call for this recommendation to be re-instated to deliver strategy recommendation 46: "We will make sure that all people with cancer have equitable access to psychological support which is tailored and specific to their needs."
Theme 4: Implementation	
5	Do you agree that these recommendations will enable delivery of the 10 year strategy? Yes Do you have any further comments? **Funding** Our major concern is the sentence in the Minister's foreword which says the proposals in this document are unfunded. Cancer Focus NI welcomes the Strategy but understands that it can only be implemented effectively if it is fully resourced. Therefore, we

	are seeking a commitment from the Health Minister and the Executive to guarantee the recurring funding needed to deliver the Strategy's recommendations. In addition, there needs to be clarity on how budget will be prioritised across the wide range of competing demands for resources. For example, how will cost effectiveness of prevention services be considered in relation to costs of diagnosis, treatments and support? How does the strategy propose to handle the additional cost of the new, anticancer drugs such as the monoclonal antibodies when they are recommended (by NICE) for specific patient groups? We would welcome commitments from The Executive on this vital issue in the upcoming Spending Review. We welcome the comments of the Finance Minister on October 14th. **Timeframes** There are little in the way of specific time frames to implement the various proposals in the strategy. Specific, timebound actions are required. This strategy's implementation must also link seamlessly with the Rebuilding Services Report post-covid (June 2021). It is clear now that covid has had a huge adverse impact on cancer patients' diagnosis, treatment, and prognosis. **Workforce planning** Developing an appropriately skilled workforce in a post pandemic environment will be very difficult unless there is robust plan in place that involves educational bodies and associated funding. GPs are essential in this strategy yet there is a shortage of all doctors, GPs, and specialists. We recognise the increased student numbers in QUB this academic year and the investment by the Executive in the new UU school of medicine. However, while the enhanced student numbers are very welcome, it must be recognised that there will be a very significant time lag before this investment makes an impact on front line delivery, by which time this 10-year report will be' time-expired'. Furthermore, there is a major problem of retention of young doctors and key ancillary experts such as radiographers, pharmacists. Unless this problem is remedied--the strategy will be difficult to implement. The issue of pay parity with other jurisdictions must also be addressed.

	The Department must integrate this new strategy with the new Integrated Care Framework and with existing and pending public Health strategies. **Role of the Voluntary Sector** Charities currently play an integral role in delivering our health service and have a unique insight to the growing needs of cancer patients. Prevention, early diagnosis, specialist nurses and counsellors are just some of the areas where Cancer Charities, such as ours could play an expanded role. Cancer Focus NI are determined to continue our work on prevention, early diagnosis, patient support and public policy. On the issue of workforce planning Cancer Focus NI is a valuable resource. Cancer Focus has many years' experience in developing, delivering, and evaluating a wide range of cancer prevention and patient support training programmes and look forward to providing continued support to Undergraduate and Post graduate training in Medicine, Nursing, PAMs and Health Improvement **Research** There is need to develop and support local cancer research. People who are treated in research active hospitals have better outcomes than those who have not. Northern Ireland is ranked globally for its cancer research, yet we are not taking advantage of our expertise to maximise cancer outcomes for our citizens. . **Data** There needs to be more emphasis on turning cancer data into intelligence to make data informed decisions - again an area of strength in NI that is not being exploited. The monitoring of diseases which affect the population including cancer, heart disease, and dementia is being hampered by the lack of regulations on the 2016 Secondary use of data Act which have yet to be developed and passed by the Assembly. Access to the indoor radon data for NI, we can use these as an additional factor for lung cancer screening (in addition to the socio-economic classification of areas)

	NiCaN What is the rationale for reorganisation of NiCaN? How will a restructured NICaN link with the groups implementing the supporting prevention strategies **Review** Continuous review will ensure focus is in the right areas, A 10-year strategy is ambitious without a robust review process in place. However, as mentioned in the paper, there needs to be robust KPI's formulated for the programme board and relevant contributory bodies to be held accountable. The input of people with lived experience of cancer and their journey through a complex diagnostic, treatment and recovery pathway is vitally important. We are encouraged to see this will be prioritised. **Thank you** Thank you for the enormous amount of work invested thus far and for considering our response. Should you require clarification or further information please contact me. We look forward to playing an active role in developing, implementing and reviewing the new strategy.

Annex C: Cancer Strategy Privacy Notice

Data Controller Name: Department of Health (DoH)
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Data Protection Officer Name: Charlene McQuillan
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Being transparent and providing accessible information to individuals about how we may use personal data is a key element of the Data Protection Act (DPA) and the EU General Data Protection Regulation (GDPR). The Department of Health (DoH) is committed to building trust and confidence in our ability to process your personal information and protect your privacy.

Purpose for processing

The Department of Health has developed a draft 10 year cancer strategy which is published for public consultation. We are encouraging organisations and institutions to respond but also people with lived experience and carers. We will process personal data provided in response to consultations for the purpose of informing the strategy. We will publish a summary of the consultation responses and, in some cases, the responses themselves but these will not contain any personal data. We will not publish the names or contact details of respondents, but will include the names of organisations responding.

Lawful basis for processing

The lawful basis we are relying on to process your personal data is Article 6(1) (e) of the GDPR, which allows us to process personal data when this is necessary for the performance of our public tasks in our capacity as a Government Department.

We will only process any special category personal data you provide, which reveals racial or ethnic origin, political opinions, religious belief, health or sexual life/orientation when it is necessary for reasons of substantial public interest under Article 9(2)(g) of the GDPR, in the exercise of the function of the department, and to monitor equality.

How will your information be used and shared

We process the information internally for the above stated purpose. We don't intend to share your personal data with any third party. Any specific requests from a third

party for us to share your personal data with them will be dealt with in accordance the provisions of the data protection laws.

How long will we keep your information

We will retain consultation response information until our work on the subject matter of the consultation is complete, and in line with the Department's approved Retention and Disposal Schedule Good Management, Good Records (GMGR).

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If you wish to request access, object or raise a complaint about how we have handled your data, you can contact our Data Protection Officer using the details above.

If you are not satisfied with our response or believe we are not processing your personal data in accordance with the law, you can complain to the Information Commissioner at:

Information Commissioner's Office
Wycliffe House
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Wilmslow Cheshire
SK9 5AF
casework@ico.org.uk