

# Report from the Assembly's All Party Group on Cancer

March 2014

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## All Party Group on Cancer Membership

### Officers of the Group

Chairperson: Thomas Buchanan MLA  
Vice-Chairperson: Cathal Ó hOisín MLA  
Secretary: Judith Cochrane MLA  
Treasurer: David McClarty MLA

### Group Members

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Thomas Buchanan, DUP  
Cathal Ó hOisín, Sinn Fein  
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### Secretariat to the APGC provided by



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The Ulster Cancer Foundation (UCF) changed its name to Cancer Focus Northern Ireland (Cancer Focus) in June 2012.

All references to UCF will be replaced by Cancer Focus in this report

## **About the All Party Group on Cancer**

The APGC was established informally in 2000 and then became a formal group in 2009. The group aims to:

- Encourage debate and update members on a range of issues, new data, trends and concerns relating to cancer
- Provide new perspectives and innovative thinking on current policy and strategies
- Find solutions and develop policies to reduce the impact of cancer on our community

In recent years the APGC has heard from a range of patients, clinicians, researchers and policy developers from the voluntary, statutory and public sectors. These stakeholders have engaged with MLAs to drive forward the agenda on cancer on many fronts. These include inequalities in men's health, tobacco and alcohol control, the role of the primary healthcare team in cancer prevention as well as access to cancer drugs in Northern Ireland (NI) and the impact of welfare reform. The full list of presentation titles are listed in Appendix 1 and the associated presentations can be accessed through the Cancer Focus website (<http://cancerfocusni.org/what-we-do/public-affairs/>).

Substantial progress has been made on a number of issues during the term of the current Assembly. These include the roll out of the Bowel Cancer Screening Programme (2012) and the Tobacco Strategy (2012-2022). There have also been substantial developments in relation to skin cancer prevention. Dr. Art O'Hagan presented to the APGC on malignant melanoma in September 2011. Since this presentation Sunbed Legislation (2012) has been introduced in addition to the launch of the Skin Cancer Strategy (2011-2021). However, there remains a need for further improvements in public health policies relating to tobacco and alcohol control, role of the primary healthcare professionals, men's health, welfare reform and equity of access to cancer treatments. The APGC has made invaluable contributions to these debates and looks forward to continued engagement with a range of stakeholders on these issues which are of real concern to every family in our community.

## **Acknowledgements**

Firstly, the APGC would like to thank the various presenters (see appendix 1) for providing their expert knowledge on a wide range of issues addressed by the group. Without their input this report would not have been possible.

We would also like to thank the various staff members at Cancer Focus namely Roisin Foster, Gerry McElwee, Liz Atkinson, Joyce Savage, Naomi Thompson, Judith West, Clare Smith, Sandra Gordon, Maresa McGettigan, Stephanie Allen and Eilish Martin for helping collate and proof read this report.

We are grateful for the input and advice from other experts in their field including Geoff Hill, Andrew Brown, Colin Fowler and Peter Hastie.

We would like to acknowledge the invaluable input of the late Francis Hamilton, a former Cancer Focus volunteer for his hard work in preparing this report. Francis willingly gave significant time to compile evidence and created a framework on which this report was based. We owe Francis a great debt of gratitude for all he accomplished.

## **Foreword**

I am honoured to have been Chair of the All Party Group on Cancer since it was reformed in 2009. Cancer is a disease which has left its mark on many families throughout NI and has become a major issue for the Health Service. In NI around 245 people each week receive the dreaded news that they have been diagnosed with cancer and on average it claims the lives of 4,000 people per year. While survival rates are increasing through intensive research and improved treatments, much more needs to be done to help and support people living with this long term illness. Our lifestyle is an important factor in the prevention of cancer and, while we cannot change our genetic makeup, we can take steps to reduce the risk of cancer by following a healthy lifestyle.

The APGC has already been instrumental in using their influence with policy makers to improve services and will continue to raise awareness through public, professional and political avenues to help improve cancer services and develop policies to reduce the impact of cancer on our communities.

*Cllr Thomas Buchanan MLA*

***Chairperson of the APGC***

Cancer Focus Northern Ireland, formerly the Ulster Cancer Foundation, is NI's longest established cancer charity, serving our community for over four decades. In the past year alone over 4,000 people accessed our cancer support services and we reached over 70,000 people with our cancer prevention messages. Our mission is to decrease the burden that cancer imposes on our society: the financial burden on our health service and on our economy, but above all the burden of ill health and loss placed on individuals and their families.

One of the approaches we take to our work is to raise public awareness of cancer - how we can reduce the incidence of cancer and how we can best support people living with the disease. Central to this is effective public health policy and a

commitment to continuous improvement in the range of treatment and services available to men, women and children with cancer in NI.

For this reason we are privileged to have held the Secretariat for the All Party Group on Cancer since 2000. I have great pleasure in presenting a summary of the work carried out by the APGC over the past year with the main evidence considered and the associated recommendations.

Tackling cancer is an All Party issue, transcending party political agendas. While there is clear evidence that links cancer to social deprivation, all of your constituents will have been affected by cancer. One in three will have a cancer diagnosis at some point in their lifetime. All will know someone, a close friend or relative who have died from the disease.

I trust that you will study the findings in this paper and endorse the recommendations so that in NI fewer people are diagnosed with cancer and that those who are have ever improving outcomes.

*Roisin Foster*

**Chief Executive Cancer Focus**

## **Executive Summary**

Cancer remains a major public health issue with approximately 12,700 local people diagnosed each year. It results in 4,047 deaths annually making it the leading cause of death in NI. However, a significant number of these cancers can be prevented, by increasing people's knowledge about the causes of cancer, helping them recognise signs and symptoms and empowering them to take control of their health. Service provision needs to be supported by intersectoral policies and legislative changes which are the responsibilities of the various government departments.

Smoking is the main preventable cause of illness and premature death in NI. It kills 2,300 local people every year. In 2012, there were 930 deaths from lung cancer alone. It has been estimated that smoking is responsible for 85% and 80% of lung cancer deaths in men and women respectively. However, 25% of the adult population currently smoke. The introduction of standardised packaging and legislation prohibiting smoking in private vehicles would be major steps towards reducing the impact of tobacco. These legislative changes should occur in conjunction with increased support for comprehensive prevention and cessation programmes.

Alcohol consumption causes 4% of all cancers. Studies have found that, on average, people who smoke and drink are up to 50 times more likely to get some types of cancer than people who neither smoke nor drink. A number of key recommendations have been made in relation to alcohol as part of "Health First: an evidence-based alcohol strategy for the UK." In particular, the report emphasises the importance of tackling the primary drivers of alcohol consumption through reducing the affordability, availability and attractiveness of alcohol products with a number of recommendations made towards achieving this including minimum pricing, larger warning labels and the prohibition of all alcohol advertising and sponsorship.

Advice regarding smoking cessation, alcohol consumption, other cancer prevention messages and screening are services that can be offered in GP Practices. However, research suggests that a lack of resources, expertise and time constraints may result in the key cancer prevention messages not being delivered consistently in



all Practices. Follow-up and support from the Practice Nurse has been found to be useful in conjunction with a GP consultation. In particular, the communication process between the patient and Practice Nurse has been highlighted as key to facilitating the delivery of these cancer prevention messages. Therefore, it is important that there is ongoing training and support for GP Practices to deliver this advice and education on cancer prevention messages.

Inequalities in cancer incidence and mortality exist between men and women, with men at greater risk of both developing and dying from cancer. Additionally, men access their primary care services less frequently than women. The barriers to accessing these services need to be measured and addressed. Primary care teams should be enabled to reach out to men and provide sufficient screening, education about symptoms of cancer and education on risk factors for cancer.

It is also vital every person who receives a cancer diagnosis has access to the most effective treatments in addition to ongoing support including financial assistance. Over the past two years, significant improvements have been made in the timeliness of the Department of Health Social Services and Public Safety (DHSSPS) process for reviewing and endorsing NICE technology appraisals. However, continued monitoring is necessary in relation to how effectively technology appraisals are being managed throughout the system. In addition, difficulties remain in accessing non-NICE approved drugs in NI which need to be addressed. Individuals living with cancer are subjected to numerous financial pressures with many unable to continue in employment as a result of their illness. The Employment and Support Allowance (ESA) and Personal Independence Payments (PIP) are two methods of providing financial assistance to cancer patients. Following changes to the welfare system, modifications have been made to the current ESA application form to help make it easier for cancer patients to be placed into the correct support group during their treatment. With both a review of ESA and training of SSA staff in NI conducted, it is now important to now ensure that this work is delivered in practice and that cancer patients are being sign posted to welfare advice as a routine part of their treatment.

This report provides background information highlighting current issues which should be addressed in relation to cancer services and details six recommendations on

which action should be taken. The APGC would encourage the formation of a joint Departmental group to ensure successful implementation of the recommendations detailed in this report.

## Recommendations

The APGC calls on the Executive to provide leadership and financial support to implement the following recommendations to improve both population health and cancer services:

1. Introduce a range of comprehensive tobacco control measures including evidenced based prevention and cessation programmes, standardised packaging for tobacco with larger pictorial health warnings and legislation prohibiting smoking in private vehicles.
2. Ensure implementation of the top ten recommendations outlined in the report “Health First: an evidence-based alcohol strategy for the UK”, in particular those relating to alcohol pricing, health warnings and advertising.
3. Ensure training and support is available for Practice Nurses and GPs to deliver advice and education on cancer prevention messages in primary care settings.
4. Engage with the voluntary, statutory, private and public sectors to develop and implement a strategy to improve men’s health and reduce cancer incidence and mortality rates.
5. Continue monitoring the process of accessing NICE approved drugs, in addition to re-evaluating the method of accessing non-NICE approved drugs in NI to ensure equity of access to cancer drugs in line with the current system in England.
6. Ensure that cancer patients are sign-posted to welfare advice as a routine part of their treatment. In addition to this, provide regular meetings between DSD and HSSPS to ensure their work remains aligned and forms like ESA50 for cancer patients are routinely signed by HSSPS staff.

## Background to Recommendations

Cancer is a group of diseases caused by rapid growth and spread of abnormal cells in the body (DHSSPS, 2011). In 2012, approximately 12,700 people were diagnosed with cancer in NI (NICR, 2014). The most common form of cancer is non melanoma skin cancer (NMSC) accounting for 29% of all cancers recorded. Apart from this type of cancer which is usually treated successfully, the most common cancers diagnosed and the associated mortality rates among men and women are shown in Table 1. These top four cancers account for almost half (46%) of all cancer deaths (Cancer Focus, 2014).

*Table 1: The most prevalent cancers (excluding NMSC) and associated mortality rates in men and women*

Gender and Cancer Type	Mortality (2012)	Incidence (2012)
<b>Male</b>		
1. Lung	527	634
2. Prostate	262	1,024
3. Colorectal	229	727
<b>Female</b>		
1. Lung	403	509
2. Breast	284	1302
3. Colorectal	187	546

(Northern Ireland Cancer Registry, 2014)

The number of people being diagnosed with cancer is increasing each year with approximately 700 more cases between 2011 and 2012 alone (NICR, 2014). It has been estimated that by 2025 there will be an increase in incidence of all cancers by up to 54% due to population growth and the increasing aging population (DHSSPS, 2008). Cancer remains the leading cause of death in NI, resulting in 4,047 deaths annually. Lung cancer is the most common cause of cancer death in both sexes taking 930 local lives each year, accounting for 23% of all cancer deaths (Cancer Focus, 2014). These figures demonstrate an undisputable fact, that cancer remains a major public health issue today.

Although cancer incidence is increasing mortality rates remain constant. The number of people surviving cancer is increasing by approximately 3.5% each year, with two thirds of people surviving after five years of initial diagnosis (NICR, 2014). The improvements in survival in NI have been influenced by a range of factors. These include the opening of The Northern Ireland Cancer Centre, improvements in cancer treatments, increased referral to oncologists and the fact that patients are now being managed by multi-disciplinary teams (DHSSPS, 2011). With increasing survival rates there is a requirement for ongoing support and access to the best available treatments in order to meet the needs of the 70,000 local people living with cancer as a long term illness (NICR, 2013; NICR, 2011).

For the apparently healthy population, cancer prevention offers the greatest potential for effective long term cancer control (WHO, 2007). Lifestyle factors affect our risk of developing cancer with many cancers being potentially avoided by making healthy lifestyle choices (WHO, 2007; DHSSPS, 2008). There is enormous potential to reduce the number of local people with a cancer diagnosis. Reduction in cancer incidence could be achieved by increasing people's knowledge about the causes of cancer, helping them recognise signs and symptoms, empowering them to take control of and improve their health.

The APGC can play a major role in maximising this potential by initiating Legislation and encouraging multi-agency groups to work together to ensure that Legislation is implemented smoothly. The APGC calls on the Executive to provide leadership and financial support to implement the following recommendations to improve both population health and cancer services:

- 1. Introduce a range of comprehensive tobacco control measures including evidenced based prevention and cessation programmes, standardised packaging for tobacco with larger pictorial health warnings and legislation prohibiting smoking in private vehicles.**

***Gerry McElwee from Cancer Focus Northern Ireland presented to the APGC on the case for plain packaging of tobacco products.***

Smoking is the main preventable cause of illness and premature death in NI, killing 2,300 local people every year (NICR, 2013). In 2011, there were 930 deaths from lung cancer alone (DHSSPS, 2011). It has been estimated that smoking is responsible for 85% and 80% of lung cancer deaths in men and women respectively (ASH, 2013; DHSSPS, 2011). The rates of smoking among adults declined between 1974 and 2007; however, since 2007 there has been no further decline, with prevalence stalling at 25% (ASH, 2013). Disparities in smoking prevalence exist between social classes making it the main contributory factor to health inequalities (DHSSPS, 2011). The most apparent gap exists between professionals and unskilled manual workers with smoking rates at 9% and 36% respectively (Health Survey Northern Ireland 2010/11). To ensure further decline in smoking prevalence, the Assembly must continue to support the DHSSPS in implementation of evidenced based prevention and cessation programmes to meet the target of 15% or less by 2020 as detailed in the 'Ten – Year Tobacco Control Strategy for Northern Ireland (DHSSPS, 2011).

The aim of a tobacco free society will never be realised unless we tackle smoking prevalence in youth (DHSSPS, 2011). Smoking behaviour is established in youth with two thirds of all smokers starting before the age of 18. Of those who take up smoking only approximately half will manage to quit before they die (Aveyard and West, 2007). Since the advertising ban in 2003 packaging is increasingly used to recruit smokers and in particular, younger smokers. Research has demonstrated that young people are attracted by packaging design and branded packaging. The

tobacco industry capitalise on this, using packaging as a marketing tool to promote products and replace smokers who quit or die (ASH, 2013).

Evidence suggests that standardised tobacco packaging enforces negative attitudes to smoking and smoking is perceived as significantly less appealing and attractive to youth (Hammond et al, 2009; Wakefield et al, 2013). In 2012, Australia implemented the standardised packaging legislation. A cross sectional study examining the effects of the standardised packaging policy on adult smokers in Australia found that standardised packaging is associated with lower smoking appeal and more urgency to quit among adult smokers (Wakefield et al, 2013).

On 8<sup>th</sup> October 2013, the European Parliament voted on a number of measures in the Tobacco Products Directive. Larger pictorial health warnings covering 65% of the pack will be implemented and packs of 10 will be removed making cigarettes less affordable to youth. The proposed ban on slim cigarettes has not yet been endorsed (McKee, 2013). The industry argues that standardised packs will lead to an increase in illicit trade in tobacco (Japan Tobacco International, 2008). This argument is unsupported by current evidence. Since the introduction of the “Tackling Tobacco Strategy” in 2000 the HM Revenue and Customs (HMRC) has been successful in making substantial reductions in the illicit cigarette market (HMRC, 2011).

The evidence of the health risks from inhaling second hand smoke is well documented. This evidence steered the smoke free legislation introduced in 2007 to protect non-smokers from exposure to second hand smoke in public places. However, there are currently no restrictions on smoking in private vehicles, even though research suggests that a single cigarette smoked in a stationary car produces a level of second hand smoke that is seven times greater than in an average bar where smoking was permitted (APPG, 2011). Second hand smoke remains a health issue for a significant number of children. The Health Minister acknowledges the health risks associated with passive smoking and refers to it as something he takes “very seriously, particularly when those affected by it are children” (DHSSPS, 2011). However, forty percent of children are exposed to cigarette smoke in the home (British Medical Association, 2007).

Exposure to second hand smoke in babies increases the risk of sudden infant death and is a cause of respiratory infections, ear infections, asthma and meningitis in children (APPG, 2011). In adults, exposure to second hand smoke increases the risk of lung cancer, chronic obstructive pulmonary disease and cardiovascular disease (APPG, 2011). Legislation prohibiting smoking in cars carrying children has been passed in jurisdictions in Canada, USA and Australia (ASH, 2012). In 2011, the Westminster APPG on smoking and health carried out an inquiry into smoking in private vehicles and made policy recommendations based on findings. The recommendations would form a useful template for introduction of a similar policy in NI.

A YouGov poll carried out in 2011 found that 78% of adults in the UK support a ban on smoking in cars carrying children, while 44% support a ban on smoking in all cars (ASH, 2012). A further YouGov poll demonstrated that up to 80% of the population are in favour of standardised tobacco packaging (ASH, 2011). These figures show the public support for legislation that we call on the assembly to enact.



- 2. Implementation of the top ten recommendations outlined in the report “Health First: an evidence-based alcohol strategy for the UK”, in particular those relating to alcohol pricing, health warnings and advertising.**

***Professor Linda Bauld from The University of Stirling presented to the APGC on “What next for the Alcohol Policy?”***

A report by Cancer Research UK (2013) suggests that 4% of cancers in the UK are caused by alcohol intake. In addition, there is evidence that alcohol is linked with increasing the risk of cancer of the mouth, pharynx and larynx; oesophagus; breast, liver and bowel (Cancer Research UK, 2013; World Cancer Research Fund, 2013). Indeed, it has been suggested that alcohol is one of the most important preventable causes of cancer in the UK after smoking (Alcohol Health Alliance UK, 2013).

A number of recommendations have been made in relation to alcohol as part of “Health First: an evidence-based alcohol strategy for the UK”, a report that was produced by the Alcohol Health Alliance and the University of Stirling in March 2013 and endorsed by over 70 organisations, including Cancer Focus (University of Stirling, 2013). These include recommendations relating to the minimum pricing per unit of alcohol; larger evidence-based health warnings; restriction of sale of alcohol in shops; appropriate rate of taxation; licensing legislation; prohibition of all alcohol advertising and sponsorship; regulation of alcohol promotion; reduction in legal limit for blood alcohol concentration; role of health and social care professionals in early identification and brief alcohol advice and routine referral to specialist alcohol services.

The “Health First: an evidence-based alcohol strategy for the UK” report particularly emphasises the importance of tackling the primary drivers of alcohol consumption through reducing the affordability, availability and attractiveness of alcohol products (University of Stirling, 2013). One of the recommendations focuses on the introduction of a minimum price of at least 50p per unit of alcohol for all alcohol sales with a mechanism to regularly review and revise this price. Evidence suggests that

many of the drinkers with the highest level of alcohol consumption obtain alcohol at cheaper prices (Black et al, 2010). Therefore, by setting a minimum unit price it is more difficult for the heaviest drinkers to maintain their alcohol consumption without increasing their costs (University of Stirling, 2013). Research has also suggested that for heavy drinkers, expense may be the main reason for not consuming alcohol (Slicker, 1997).

Another recommendation focuses on ensuring that at least one third of every alcohol product label is given over to an evidence-based health warning specified by an independent regulatory body (University of Stirling, 2013). Research has suggested that warning labels are important to raise awareness of the harm related to alcohol (Anderson et al, 2009). However, there is limited evidence for the effectiveness of current warning labels on alcohol products for producing behaviour change (Wilkinson and Room, 2009). This may be in part due to the current size of the labels. Previous research has shown that both content and design of health warning labels can influence their effectiveness (Agostinelli and Grube, 2002). The effective use of larger health warnings on tobacco products suggests that this may be a useful strategy in relation to alcohol products (Borland et al, 2009; Wilkinson and Room, 2009).

In addition, another recommendation also emphasises the importance of prohibiting all alcohol advertising and sponsorship. It is also suggested that in the short-term alcohol advertising should only be permitted in newspapers and other adult press and that the content should be limited to factual information about brand and product strength. Evidence suggests that there is a link between alcohol advertising and alcohol consumption, particularly in young people (Anderson et al, 2009; Smith and Foxcroft, 2009). Alcohol is marketed through many channels for example through mainstream media and the internet and through linking alcohol brands to sports activities and sponsorships. Banning alcohol advertisements, in addition to making alcohol more expensive and less available has been shown to be a highly cost-effective strategy for reducing harm (Anderson et al, 2009). This is similar to previous research in relation to tobacco control which found that comprehensive advertising bans are effective in reducing consumption (Saffer and Chaloupka, 2000; Blecher, 2008).

Therefore the APGC calls for the assembly to ensure implementation of the top ten recommendations outlined in the report “Health First: an evidence-based alcohol strategy for the UK”, in particular those relating to alcohol pricing, health warnings and advertising.

- 3. Ensure training and support is available for Practice Nurses and GPs to deliver advice and education on cancer prevention messages in primary care settings.**

***Professor Hugh McKenna from the University of Ulster presented to the APGC on the role of the GP and primary care nurse in the prevention of cancer.***

In the primary healthcare setting, smoking cessation and screening are cancer prevention methods offered by GP Practices (Anczak and Nagler, 2003; McIlfatrick et al, 2013). In addition, to the provision of these services, information on the other risk factors for cancer including alcohol consumption, obesity, diet and physical exercise are also provided to patients through the Practice (McIlfatrick et al, 2013).

However, although a number of GPs are providing cancer prevention advice this is below the recommended national guidelines (McEwen and West, 2001). General Practitioners report being mainly opportunistic in relation to cancer prevention, with preventative activities taking up only approximately 16% of clinical time (McAvoy et al, 1999). In addition, GPs report a number of perceived barriers to providing cancer prevention activities including lack of time, expertise and resources (Ganry and Boche, 2004; McIlfatrick et al, 2013).

The interaction between the patient and Practice Nurse has been highlighted as a facilitator to cancer prevention work (McIlfatrick et al, 2013). Many GPs perceive Practice Nurses to be better placed to deliver cancer prevention activities with 20 minutes typically allocated for a patient consultation (McIlfatrick et al, 2013). In addition, GPs often perceive Practice Nurses to have more educational and preventative roles in comparison to the role of a GP which tends to be more interventionist (McIlfatrick et al, 2013). Longer consultation times can often lead to more in-depth communication between the Practice Nurse and patient, resulting in many of the activities being individualised and tailored to patient need (McIlfatrick et al, 2013). A study by Drury et al (1988) found that good communication skills were one of the main qualities sought by patients when attending a healthcare provider,

particularly the time spent with the patient, the ability of the healthcare professional to listen to the patient and their ability to make the patient feel at ease.

Research has suggested that follow-up and support from the Practice Nurse can be useful in conjunction with the consultation provided by the GP (Austoker et al, 1994). However, there still remains a significant gap between current knowledge and practice with both GPs and Practice Nurses highlighting the need for further training and support to develop their current knowledge of cancer prevention and other health promotion activities and their confidence in delivering these services (McAvoy et al, 1999; Brotons et al, 2005; McIlfatrick et al, 2013).

It is of vital importance that primary care settings are supported in the delivery of cancer prevention messages. As both GPs and Practice Nurses are both in frequent contact with members of the public, they have a key role to play in cancer prevention and early detection of cancer (Ganry and Boche, 2004; McIlfatrick et al, 2013). Delivery of smoking cessation services is of particular importance as tobacco usage is one of the main risk factors for cancer (World Health Organisation, 2007) and these services are considered to be one of the most cost-effective treatments within the National Health Service (NHS) (Stapleton, 2001). In addition, advice on other cancer prevention messages is also important as diet is considered to be the second biggest contributory factor to developing cancer (DHSSPS, 2008). Hence, the APGC calls for training and support for Practice Nurses and GPs to deliver advice and education on cancer prevention messages in primary care settings.

**4. Engage with the voluntary, statutory, private and public sectors to develop and implement a strategy to improve men's health and reduce cancer incidence and mortality rates.**

***Professor Ian Banks from the European Men's Health Forum presented to the APGC on Men and Cancer***

Men die on average almost 4.5 years younger than women and have higher death rates at all ages and for all leading causes of death (Men's Health Forum, 2004). Cancer represents a significant proportion of the excess burden of ill health experienced by men (Clarke et al, 2013). Men are at a significantly higher risk of developing and dying from nearly all of the common cancers that occur in both sexes (Thomson et al, 2013). Standardised cancer death rates in NI are significantly higher in men than in women at 214 per 100,000 compared to 149 per 100,000 respectively (NICR, 2013). Men are approximately twice as likely as women to die from liver cancer and three times as likely to die from oesophageal cancer (Cancer Research UK, 2013). These statistics reveal the scale of the problem and highlight the fact that policy changes are required to improve the health of men in our society. 'A report on the Excess Burden of Cancer among Men in the Republic of Ireland (2013)' and 'Men and Cancer: Saving Lives (2013)' are two recent publications which detail the excess burden of cancer among men and highlight the need for policy change.

The reasons for the gender disparity in cancer incidence and mortality have not been fully established. David Wilkins (Policy officer for The Men's Health Forum in England and Wales) states that "most of the explanations for men's higher rates of death from cancer are to do with lifestyle differences between the sexes". Smoking and alcohol consumption both have stronger associations with cancer in men than in women. Research carried out in the Republic of Ireland highlighted that men are more likely to exceed the recommended daily intake of red meat and dairy products, become overweight earlier in life and are less likely to consider reducing calorie intake to lose weight (Clarke et al, 2013). In NI, two thirds of the male population are overweight or obese and one quarter exceed the recommended weekly alcohol

intake (British Medical Association, 2012). In general, men are more physically active than women but over half of the male population are not achieving the current recommended physical activity guidelines for health (British Heart Foundation, 2012).

There is a requirement to improve men's lifestyles in order to improve their overall health and lower disease risk. Recommendations one, two and three set out in this document are not targeted specifically at men but if enacted would undoubtedly have a positive impact on men's health.

In addition, men use primary care services 20% less frequently than women (British Medical Association, 2012). This pattern is consistent across the UK and Europe. Prof. Ian Banks has highlighted that men are deterred from engaging with primary care services as many men perceive "seeking help as incompatible with masculine 'norms' of strength, stoicism and self-reliance" (Banks and Baker, 2013). In addition, men are more likely to engage with primary care for curative reasons rather than preventative reasons (Clarke et al, 2013). Men's unwillingness to access primary care services is reinforced by a number of practical barriers such as waiting times, logistical issues and lack of extended opening hours (Banks and Baker, 2013). The barriers in accessing primary care services need to be measured in the context of NI and a strategy should incorporate methods in which to overcome the identified barriers. Men should have access to primary health care services in a supportive environment. Primary health care teams should reach out to men and provide sufficient screening and raise awareness of symptoms of cancer so that they seek help at early stage. This is particularly important for younger men. This is not only the job of the primary health care team; voluntary and public bodies should also be encouraged to raise awareness of cancer symptoms. These messages need to penetrate all levels of society in order to make significant impact.

At present, the Republic of Ireland is the only country in Europe to have a national policy dedicated to improving men's health. In light of the evidence documented in recent reports and highlighted here, the APGC call on the DHSSPS and Executive to work in partnership with the Men's Health Forum in Ireland, Cancer Focus and other statutory and public bodies to develop a strategy to improve the health of men

across NI. This strategy would ensure a positive working climate for service providers and practitioners, create an expectation that the poor state of men's health can be effectively addressed, lead the way to an increase in both the quantity and quality of interventions tailored for men and ultimately reduce the incidence and mortality rates of cancer and other chronic diseases.



- 5. Continue monitoring the process of accessing NICE approved drugs, in addition to re-evaluating the method of accessing non-NICE approved drugs in Northern Ireland to ensure equity of access to cancer drugs in line with the current system in England.**

***Dr. Martin Eatock from Belfast City Hospital presented to the APGC on access to cancer drugs in Northern Ireland.***

Advice on new and existing cancer drugs is usually provided by the National Institute for Clinical Excellence (NICE). The guidance provided states which cancer treatments should be made available through the NHS that are both effective and cost-effective. This ensures treatments are made available quickly to patients and variations in the availability of these treatments are minimised (MacMillan, 2012; NICE, 2013).

In 2011, the Rarer Cancers Foundation highlighted the lengthening delays for accessing NICE-approved drugs which on average was more than six months. Following this, the Northern Ireland Health Minister, Edwin Poots confirmed in the Assembly that there would be a new process for improving the availability of treatments approved by NICE which would be effective from the 28<sup>th</sup> September 2011 (Northern Ireland Assembly, 2011).

Under the new system, there is now a single process for endorsing NICE guidelines with guidance from NICE initially referred to the Chief Medical Officer for approval (DHSSPS, 2011). Following this approval, the Department issues the endorsed guidance to the HSC Board, requesting that the Board prepare a Commissioning Plan in respect of the Technology Appraisals (DHSSPS, 2011).

There have been significant improvements since 2011, relating to the timeliness in which NICE technology appraisals are reviewed and endorsed by the DHSSPS. In addition, the new system has enabled the DHSSPS to address any outstanding technology appraisals issued by NICE (Cancer Focus, 2013). Since 2011, 71 technology appraisals have been reviewed and endorsed by the DHSSPS, with the

median time for achieving this lasting 22 days rather than 290 days as previously reported (Cancer Focus, 2013).

It is also important that this is translated into ensuring that the latest clinically-effective treatments are available for patients. This means ensuring there is no delay in implementation of individual commissioning plans by the Health and Social Care (HSC) Trusts. Hence, there is a need for continued monitoring and evaluation on the effectiveness of all stages of the management of a technology appraisal (Cancer Focus, 2013). The DHSSPS has confirmed that reports are due to be published by both the HSC Board and the Guidelines and Audit Implementation Network (GAIN) (Northern Ireland Assembly, 2012; DHSSPS, 2013) therefore the APGC calls for continued monitoring of the process for adopting NICE approved drugs in NI.

There are also difficulties in accessing non-NICE approved drugs for patients in NI. There are 22 cancer treatments which are not routinely available, as a result of not yet being approved by NICE (Cancer Focus, 2013). Post script this figure is now 38 treatments – (NHS England, 2014). This is in stark contrast to England where the Cancer Drugs Fund (CDF) has been established to give patients access to those treatments that are not routinely available on the NHS because they may not have been appraised by NICE or have been deemed to be not as effective or cost-effective (Cancer Research UK, 2013). The CDF aims to reduce inequalities in accessing these treatments; however, crucially it only applies to patients in England.

The only way patients in NI can gain access to these treatments is through an individual funding request (IFR) made by their clinician on their behalf. An individual funding request is a request for an individual to access a treatment that is not normally commissioned or funded in Northern Ireland (HSC Board, 2011). However the requests are only considered by the HSC Board if exceptional clinical circumstances can be identified i.e. if the patient is significantly different in clinical circumstances to the general population of patients with the condition and if the patient is likely to gain significantly more benefit from the intervention than might be normally expected for patients with that condition (HSC Board, 2011). The Rarer Cancers Foundation (2011) has previously highlighted the difficulties in securing

funding for treatment via this route. Research carried out by Cancer Focus to establish the views of cancer specialists in NI reported that due to length of the time required to fill out individual funding requests, some cancer patients are missing out on vital life-prolonging cancer medicines. Forty percent of survey respondents also reported receiving a diagnosis too late to initiate treatment for a medicine that would be routinely available in England (Cancer Focus, 2011). Clinicians may also be unlikely to submit an application for an individual funding request if they feel the patient will not meet the criteria for an exceptional case, even if they deem that the treatment will be clinically appropriate for the patient (Rarer Cancers Foundation, 2012).

These barriers demonstrate the need for action to ensure all patients in NI have the same access to the latest cancer treatments, as those in England. The APGC calls for a review of the process for accessing non-NICE approved drugs in NI to ensure equity of access to cancer drugs in line with the current system in England.

**6. Ensure that Cancer patients are sign-posted to welfare advice as a routine part of their treatment. In addition to this, provide regular meetings between DSD and HSSPS to ensure their work remains aligned and forms like ESA50 for cancer patients are routinely signed by HSSPS staff.**

***Heather Monteverde from Macmillan gave a presentation outlining the background over recent years to welfare reform, the lobbying and changes made to the UK Welfare Bill through its passage, and ongoing work for the future.***

Research has shown the financial impact of receiving a cancer diagnosis with some patients on average £290 worse off each month in NI as a result of their illness (Macmillan, 2013). Many are unable to continue in employment hence facing a loss of income (Macmillan, 2013). In addition, there may be numerous costs associated with their illness, for example regular trips for medical appointments (Macmillan, 2013). It is therefore important that patients receive adequate financial support at this time.

The Employment and Support Allowance (ESA) is one example of this financial support. The ESA is designed to provide support to those who are unable to continue in employment (Macmillan, 2013). In addition, the Disability Living Allowance (DLA) to be replaced with the Personal Independence Payment (PIP) under the proposed changes to the welfare reform is another method of providing financial help towards some of the extra costs arising from a health condition or disability (Macmillan, 2013).

On 29 June 2010, the Secretary of State for Work and Pensions appointed Professor Malcolm Harrington, an occupational health specialist, to carry out the first Independent Review into Work Capability Assessment (WCA). Hence, from 2010 to 2013, a review was conducted by Professor Harrington and a number of recommendations made for implementation by the government (Harrington, 2012).

At the same time as this review was being carried out the Welfare Bill was making its way through Westminster. Although significant progress was made during the Bill stages to ensure that under the “Welfare Reform Act 2012” people can claim PIP three months after diagnosis rather than six months as originally proposed by the government (Department for Work & Pensions, 2012), a time-limit of 12 months was still set for contributory ESA for those in the Work Related Activity Group (Department for Work & Pensions, 2012).

However, Lord Freud later conceded in the Lords that ‘the intention of our proposals is to introduce a presumption that most people being treated for cancer should be in the support group unless the evidence indicates that, exceptionally, the debilitating effects of treatment are likely to be more limited. We would expect this to increase the number of individuals going into the support group and to reduce the number of people called to attend a face-to-face assessment.’ (House of Lords, 2012)

On the 20th September 2012 a press release from Department for Social Development Minister Nelson McCausland welcomed the rule change to support cancer patients: “New proposals, published by the Department for Work and Pensions (DWP) in Great Britain, will mean that hundreds more people in NI, and across the UK, who are awaiting, receiving, or recovering from any form of chemotherapy or radiotherapy for cancer will be placed in the support group for Employment and Support Allowance (ESA). Here they will get the financial support they need while unable to work”. Minister McCausland said: “This is a very welcome step and it is one that I have been calling for, for some time (NI Executive, 2012).

Following this statement from Ministers at UK and NI level, and the work from Professor Harrington, the DWP and the Social Security Agency (SSA) agreed to modify the ESA Application form to make it easier and more straightforward for cancer patients to get put into the correct support group during their treatment. In addition, SSA staff in NI have also been provided with training by Macmillan, to understand the new system and how to make it work for cancer patients.

Hence, with so much work having been done in lobbying governments across the UK, campaigning with Professor Harrington (and now his successor Dr Paul Litchfield) on reviewing ESA, and training SSA staff in NI it is now important to ensure that this work is delivered on the ground by both health service staff who need to sign the forms for cancer patients and DSD/SSA staff who administer them.

The APGC recognises the important role played by Macmillan Cancer Support and others in ensuring access to benefits advice and support. Therefore the APGC calls for the Assembly to ensure that cancer patients are sign posted to welfare advice as a routine part of their treatment with advice services being located inside the health environment being a key point. In addition, the APGC calls for the DSD and HSSPS to meet regularly to ensure their work remains aligned and to ensure forms like ESA50 for cancer patients are being routinely signed by HSSPS staff.

## **Conclusion**

The aim of the APGC is to reduce the impact of cancer in our society. This requires a comprehensive approach. Reduction in cancer incidence can largely be achieved by a full implementation of the “Fit and Well Changing Lives Strategy (2012-2022)”, by enhancing the role of the primary care team in cancer prevention and enacting the aforementioned legislative changes in relation to smoking and alcohol.

There is irrefutable evidence in the case for improvements in cancer care. The methods for accessing NICE approved and non-NICE approved drugs should be continually monitored and re-evaluated respectively to ensure that cancer patients are not missing out on life saving medication and that equality exists between provisions of cancer services throughout the UK. The same patients should be supported financially and be given adequate information and support about the benefits that they are entitled throughout their cancer journey. The action points set out in this document have been developed in accordance with current evidence, some of the legislative changes that we call for have been tried and tested in other countries and have proven successful. It is for this reason that these recommendations should be enacted without delay which will bring us closer to achieving our ultimate goal.

The “Fit and Well Changing Lives Strategy (2012-2022)” when published should provide a useful framework in which to implement the recommendations (DHSSPS, 2012). It should be acknowledged that essential changes need to occur across all levels of society with intersectoral collaboration occurring between statutory, voluntary and public bodies. This is a joint effort which would be more effectively enacted by a cross Departmental group. The APGC would encourage the formation of a joint Departmental group to coordinate the necessary action from all the relevant government departments to help reduce the impact of cancer on our society.

The APGC will continue to help educate, inform and influence the strategies that will be taken forward by the Executive and will support all efforts to address cancer in the future.

## Appendix 1

### All Party Group on Cancer Presentations

Date	Topic	Presenter
28/6/11	Access to Cancer Drugs in Northern Ireland	Dr Martin Eatock, Belfast City Hospital
20/9/11	Malignant Melanoma in Northern Ireland	Dr Art O'Hagan, Consultant Dermatologist Craigavon Area Hospital
8/11/11	Cancer Care in Northern Ireland – A Decade of Change	Dr.David Donnelly and Mr. Conan Donnelly NI Cancer Registry
21/2/12	Cancer Control in Europe	Emma Woodford, European Cancer Leagues
15/5/12	Review and Plan Ahead	No Presentation
19/6/12	The Case for Plain Packaging of Tobacco Products	Gerry McElwee Cancer Focus
9/10/12	Fit and Well Changing Lives	Dr Michael McBride, Chief Medical Officer DHSSPSNI
20/11/12	Making All the Difference – Men and Cancer	Professor Ian Banks, European Mens Health Forum
5/3/13	What Next for Alcohol Policy?	Professor Linda Bauld, University of Stirling
14/5/13	Cancer Patients and the Welfare Reform	Heather Monteverde, General Manager Macmillan
25/6/13	Investigating the Actual and Potential Role of the GP and Primary Care Nurse in the Prevention of Cancer	Professor Hugh McKenna, University of Ulster

**Note:** The associated power point presentations can be accessed through the Cancer

Focus website ([www.cancerfocusni.org](http://www.cancerfocusni.org))



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