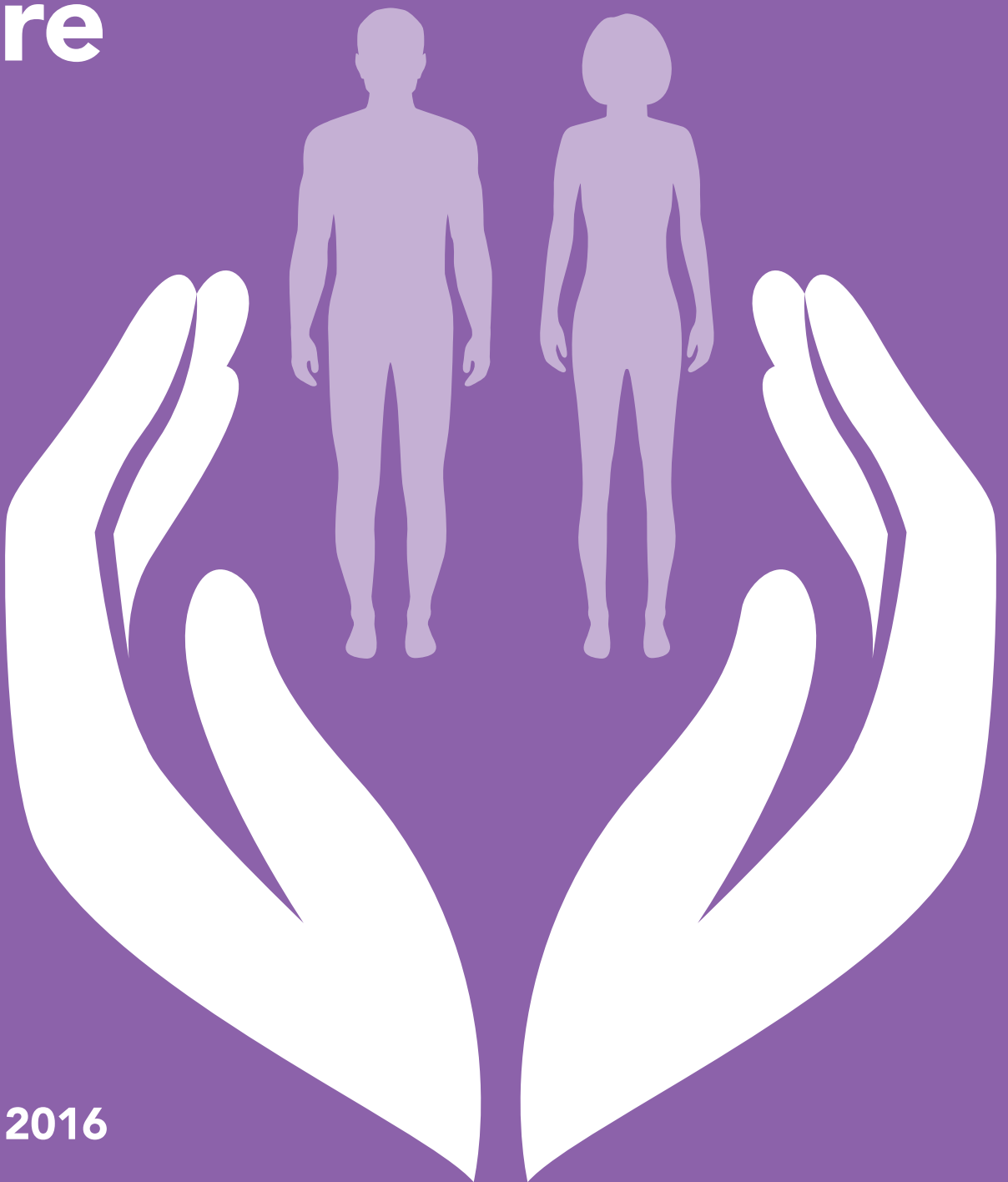




Unionist
Ulster Unionist Party

Doing what's right for Northern Ireland

Cancer Care



March 2016

Introduction by Party Leader



I am very pleased to present to you the fourth of our policy papers.

Cancer is the number one cause of death here and sadly every year up to 4,000 people succumb to the ravages of the disease.

Very few people across Northern Ireland have managed to avoid being touched by cancer, be it personally or through witnessing the impact it has on a family member or friend. We all know what an intensely cruel and unforgiving disease it can be.

A cancer diagnosis, along with the often gruelling affects of treatment, not only rocks the life of the patient, but also all of those around them. Few words, if any, are able to strike as much fear as a single whisper of cancer.

Yet the reality is more than one in three of us will be diagnosed with cancer at some point in our lives, and in only 5 years' time that rate will have risen to almost one in two. Look around you look at your family, your friends, your work colleagues – half could be affected by the disease.

The days of cancer being taboo or only affecting other families are gone. We all need to become aware of the signs and symptoms of it and we need to ensure that our local health and social care system is equipped to deal with its burgeoning incidence rates. This is particularly important as we modify the local system to respond to our ageing population.

However whilst the number of people being diagnosed with cancer here is growing year-on-year, we should take some comfort that rapid advances in the diagnosis and treatment of cancer means that more of us are beating the disease than ever before. It certainly is no longer the death sentence it once was and with every passing year more people with a past diagnosis are living full and healthy lives.

In addition we know that almost half of all cancers are preventable and we also know what the factors are that can increase the risk – smoking and obesity, genetics and overexposure to certain toxins and sunlight. It is up to us as society to remain cognisant of that.

No matter the cause or strand of the disease, Northern Ireland cancer patients are fortunate to have the local care and support network that they do. The Cancer Centre in Belfast is recognised for its expertise and therefore patients from all over the Province are content to travel to it. The new radiotherapy unit at Altnagelvin will however bring the treatment closer to many.

It would be remiss of me not to mention the invaluable work of the local cancer charities, for without which patients and their families would be lost and the trailblazing local research would not be able to proceed.

The scale of the disease, and the even greater prominence it is going to display over the years to come means that cancer prevention, early detection and timely treatment must remain a top priority within the health agenda for Northern Ireland. In this document you will see how the Ulster Unionist Party proposes to respond to feed into that process.

Mike Nesbitt
Leader, Ulster Unionist Party

Overview



The scale of the challenge in numbers

Every year approximately **9,000** people are diagnosed with cancer in Northern Ireland. Over **4,000** people die as a result of the disease here each year. This is equivalent to more than 1 in 4 of all deaths in Northern Ireland every year.

The overall incidence of cancer is **14%** above the Northern Ireland average in the most deprived communities with lung cancer a startling **68%** above average.

There are currently over **70,000** people living with a past cancer diagnosis in Northern Ireland.

The number of people living with cancer and the consequences of it is expected to rise to over **110,000** by 2030.

The five year survival rates for all cancers are increasing, but there is still much room for improvement for some. For instance the pancreatic cancer five-year survival rate in Northern Ireland is still only **5.0%**.

Northern Ireland's slipping performance

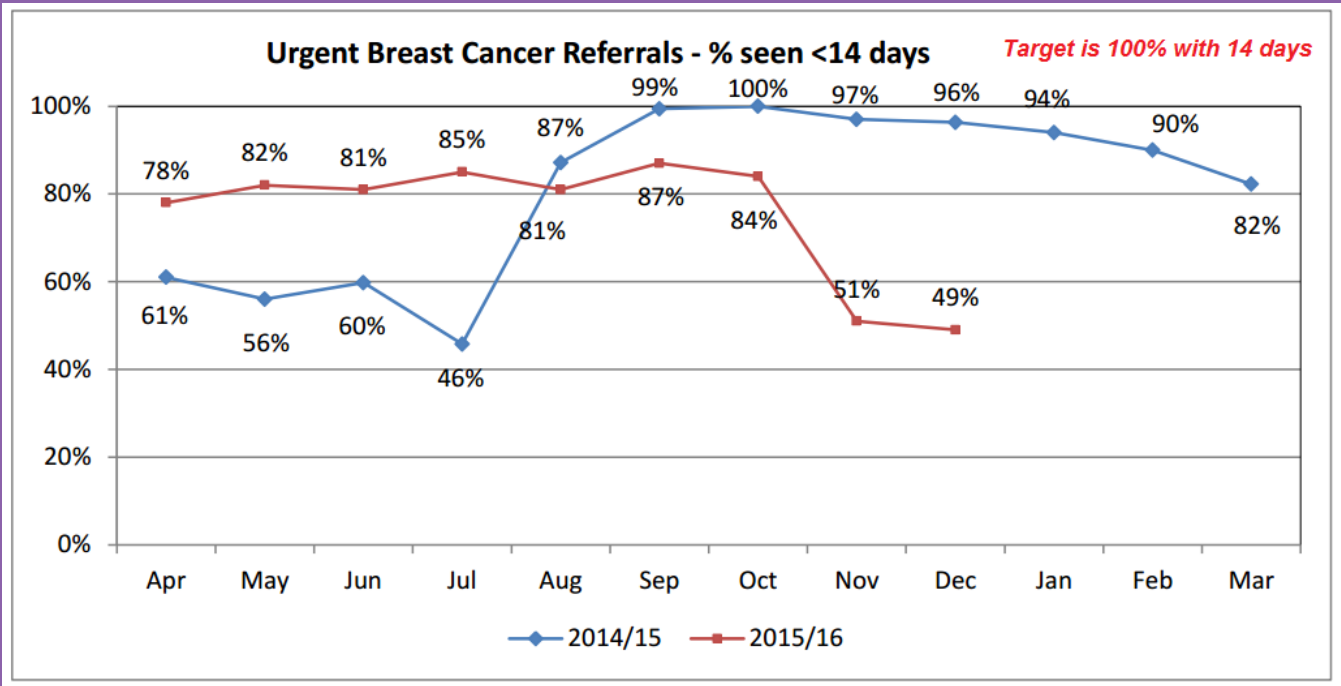
Cancer waiting time standards have helped drive service improvement and outcomes for patients. In addition, targets are set for cancer treatment because there is very sound medical evidence that confirms the longer a patient has to wait for treatment, the greater the risk that they may ultimately come to harm.

Unfortunately however, despite it being a disease that thrives during any avoidable delay in treatment, patients in Northern Ireland are currently experiencing a frightening deterioration in the overall performance against these targets.

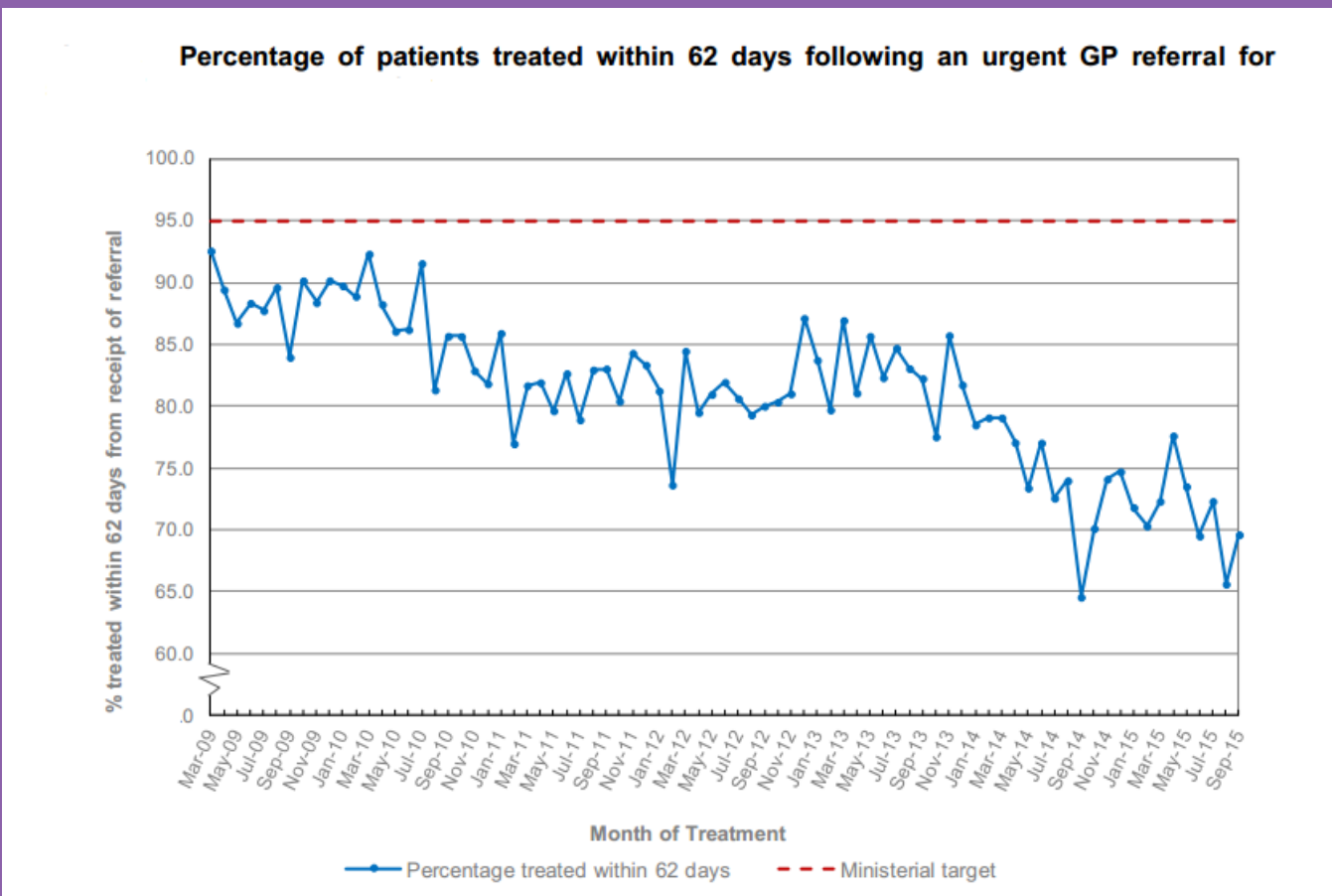
The Ministerial target on waiting times for a first assessment with a breast cancer specialist for instance is that all urgent breast cancer referrals should be seen within 14 days. The reality is however, that in December 2015, only 49% of urgent referrals were seen within 14 days. In addition there was an unacceptable degree of variation across each of the Health Trusts, with only 11% of referrals being seen on time in the Northern Trust area. In the Belfast Health Trust only 24% were seen on time, and tragically of all those who were not 121 were later diagnosed with breast cancer.

The target on waiting times for treatment following an urgent GP referral for suspected cancer requires that at least 95% of patients should begin their first treatment within 62 days. The stark reality is however that of the suspected cancer patients treated during September 2015, only 69.5% received treatment on time.

Of the 109 people that had waited longer than the target of 62 days for treatment in that month, 32 were later diagnosed with urological cancer, another 32 with gastrointestinal cancer, 18 with skin cancer, 8 with head/neck cancer, 7 with gynae cancer, 7 with lung cancer, 3 with breast cancer and 1 with haematological cancer.



Source: Health and Social Care Board



Source: Department of Health, Social Services and Public Safety

How the Ulster Unionist Party would do things differently



1. Implement a Northern Ireland Cancer Strategy

Last year in England the Independent Cancer Taskforce published a major strategy for improving cancer outcomes. If these ambitious, yet realisable, recommendations are implemented up to 30,000 more lives could be saved each year from 2020. If an equally ambitious plan were adopted and implemented here in Northern Ireland, proportionately that could mean up to a 1,000 saved lives. Saving 1 life is a reason enough to do something differently, but now we have 1,000 reasons to do so.

In addition Scotland launched their new strategy earlier this month and Wales will launch theirs later in 2016. We need to act now to ensure Northern Ireland addresses the point we will shortly be the only region of the United Kingdom without a comprehensive cancer strategy.

That is why the Ulster Unionist Party will prioritise the development of an ambitious, forward-thinking and target driven strategy that would build around key pillars of enhanced prevention, swifter diagnosis and modernised NHS services in order to deliver better outcomes for our cancer patients.

This new strategy and its accompanying resourced and measurable action plan would then become the blueprint for cancer services for the following 10 years.

2. Detecting and treating cancer earlier

The sooner cancer is detected and treated, the easier it is to treat and the better the prospect the patient has of living a long and healthy life beyond the disease. Finding and treating cancer earlier

saves lives and diagnosing at earlier stages should therefore remain central to how we approach the disease.

There are incidences every day of people being given an avoidable prognosis of terminal cancer and whilst there are a wide variety of causes of late detection, the reality for many people is that they are still going undiagnosed simply because their symptoms went undetected or unrecognised.

Emergency admissions to hospital is neither the time nor place for a cancer diagnosis, yet that is approximately how 1 in 4 cancers are found.

We would:

- **Develop new training programmes for primary care professionals to improve their awareness of the signs and symptoms of cancer;**
- **Improve GP access to diagnostics by giving them the power to refer directly for key diagnostic tests such as MRI/CT scans, chest x-rays, and non-obstetric ultrasounds;**
- **Increase the uptake of the national cancer screening programmes;**
- **Reduce the age for the bowel screening programme to those aged 55 and switch to the FIT test for bowel screening program in order to increase uptake;**
- **Launch a pilot on the use of flexible sigmoidoscopy as a one off test for those aged 55;**
- **Adopt the National Screening Committee recommendation to change the test used in cervical cancer screening programme from cytology to HPV.**



3. Preparing for an older population

Whilst anyone of any age can develop cancer, including heartbreakingly the very youngest in society, two thirds of those who are affected with cancer are aged 65 years and older.

Whilst it is to be welcomed that people are living for longer, one impact of this is Northern Ireland has a rapidly ageing population. This fundamental change in local demographics will be accompanied with an increased incidence of cancer. That in turn is going to place additional pressures on our already struggling cancer services.

All the evidence shows that cancer mortality levels are dropping as a result of ever improving treatment, but we remain deeply concerned about care for older patients. Age should not be a barrier to patients getting the treatment and support that would give them the best chance of beating cancer.

We would:

- **Ensure treatment is offered by clinical assessment and need, not on the basis of age;**
- **Improve the connection for cancer patients between primary, social care and secondary care providers in order to deliver the medical and practical support such as suitable transport to chemo appointments;**
- **Improve respite care for older cancer patients who are also the carer for a spouse;**
- **Make it easier for older people to take part in clinical trials in order to build up a medical evidence base.**

4. Meeting the needs of children with cancer

The types of cancer that affects children are very different to those that affect adults and even older teenagers. Whilst cancers such as leukaemia are better represented in research literature than other diseases, on the whole there remains much yet to learn.

The detection and the survival rate for childhood cancers has improved dramatically over the last 40 years – 82% of children now survive a cancer diagnosis. But the impact of a cancer diagnosis on a child and their family is enormous, and there can be ongoing health problems arising from the cancer diagnosis itself or treatment. Children and their families need to be supported through not only their treatment, but also afterwards.

Nevertheless, despite the fundamental challenges that remain in treating childhood cancers the outlook for children with cancer in Northern Ireland has improved dramatically over the last number of decades.

We would:

- **Ensure children and young people with a cancer diagnosis are able to access quality alternative provision to continue their education;**
- **Extend the HPV vaccination programme to include adolescent boys;**
- **Promote the proven medical benefits for young children of breastfeeding age;**
- **Ensure the new system of Personal Independence Payments responds quickly so that young people with cancer no longer have to endure the delays experienced with the Disability Living Allowance.**

5. A more ambitious approach to tobacco

Smoking is the single greatest cause of preventable illness and premature death in Northern Ireland, killing round 2,300 people each year. It is the most preventable cause of cancer here and for those it doesn't eventually kill it often leaves a myriad of lasting health implications.

The simple reality is if people want to reduce their risk of developing cancer the very first thing they should do is quit smoking.



Whilst we were glad to see the 10 year Tobacco Control Strategy for Northern Ireland, including its broad focus on creating a tobacco free society, smoking levels among pregnant woman and vulnerable and disadvantaged groups remain particularly concerning. We think it is time to go further.

We would:

- **Set a target date of 2035 for Northern Ireland to be tobacco free with a recorded incidence of less than 5%;**
- **Ring-fence spending on tobacco prevention and cessation services given how extremely cost-effective they are;**
- **Support the introduction of a UK levy on tobacco manufacturers and importers;**
- **Invest in programs to promote smoking cessation, principally at primary care level;**
- **Introduce a rigid regulatory framework for electronic cigarettes, which are currently attracting a new generation of smokers, in order to control the safety, sale and promotion of the products.**

6. Equal access to Clinical Nurse Specialists

A diagnosis of cancer can be one of the most frightening periods of anyone's life. Despite positive outcomes increasing, too many people are being forced to face the disease without specialist care and support.

Clinical Nurse Specialists play an absolutely essential role in the delivery of local cancer care. They show the compassion that patients should expect at such a time and allow patients to receive care much closer to home.

Despite the value of these nurses, regrettably Northern Ireland has the lowest provision in the UK. In addition then there is a wholly unacceptable level of variation amongst a range of the cancer types

across each of the five local Health Trusts. We would:

- **Ensure that every patient diagnosed with cancer has access to a Clinical Nurse Specialist;**
- **Improve the level of sharing of resources across Trust areas to bring the current abhorrent postcode lottery to an end.**

7. Adoption of NICE approved drugs

The National Institute for Health and Care Excellence is responsible for issuing guidance for which drugs and treatments should be available on the NHS across the United Kingdom. The local Health and Social Care Board is provided with the guidance, however the problem then lies with the length of time it takes for the impact of the drugs to be analyzed here and then approved.

The excessive delays in adopting NICE approved drugs here has resulted in a further deepening of the postcode lottery across the United Kingdom. As a result cancer patients in Northern Ireland continue to suffer.

In addition, not only have local cancer patients been unfairly denied life-saving drugs that their counterparts in Great Britain received through the NHS, but the IFR mechanism previously in place for drugs that are not readily NICE approved was inherently flawed.

We would:

- **Commit to the automatic and timely approval of NICE approved cancer treatments;**
- **Introduce a new clinically based system for evaluating requests for specialist medicines not approved by NICE.**

8. Supporting our research base

Through the efforts of our local academic institutions, charities and the Centre for Cancer Research and



Cell Biology, Northern Ireland has become a global leader in cancer research. In addition breakthroughs by local pharmaceutical and biotec firms are at the forefront of the drive to find new ways to treat cancer. New drugs and techniques created in Northern Ireland have saved countless lives all over the world.

In addition our local research industry makes a major economic contribution by supporting and providing employment, continual major financial investment and attracting new business partnerships. Research into cancer is the largest type of medical research undertaken in Northern Ireland and it is therefore important that we maintain our position as a leader in this field.

We would:

- **Continue to grow Northern Ireland's research sector by ensuring that the Health and Social Care R&D Division funding for cancer research is ring-fenced, and actively encourage further funding from charity and industry partners;**
- **Ensure that each of the Health and Social Care Trusts adopt a culture of embracing and supporting clinical research;**
- **Improve the information about available trials in order to ensure every patient who is eligible to take part is given a fair opportunity. We would fully support the 'It's OK to Ask' campaign to encourage patients to inquire about trials that might be suitable for them;**
- **Resolve the consistent staffing challenges within the Trials Unit by allowing it to recruit and retain new permanent staff in order to deliver the maximum number and range of clinical trials.**

9. Rotating cancer awareness campaigns

Prevention is always better than cure and that is particularly relevant for the cash-strapped NHS in Northern Ireland. The Public Health Agency, a body

that former Ulster Unionist Health Minister Michael McGimpsey created, does exceptional work at enhancing focus on public health and wellbeing.

Whilst cancer is no longer a taboo subject to talk about, worryingly there is still a major lack of knowledge of the signs and symptoms of many of our cancer types. As a result people often wait too long to get a diagnosis and therefore the prospects of a successful outcome are diminished.

PHA campaigns have been effective at raising awareness of cancer signs and symptoms and encouraging those with any suspicions to seek help quickly and not to delay.

We would:

- **Ring-fence funding for the ongoing 'Be Cancer Aware' programme to focus on a range of cancer types;**
- **Ensure that future awareness campaigns targets those in disadvantaged areas that may be less likely to know the signs and symptoms of cancer, and also less likely to see their GP.**

10. End of life care

Cancer remains the biggest cause of death in Northern Ireland and yet there are still too many people with a terminal prognosis not receiving the end of life, or palliative, care that they need. One in four people who need this care are not accessing it – it is estimated that is nearly 3,000 people.

For instance, the inadequacy of social care means some patients with a terminal diagnosis pass away in hospital because it took too long to put in place suitable arrangements to allow them to be safely discharged home.

People who are nearing the end of their life need to be supported to make decisions that allow them to be fully prepared. As a society we could do much better at being able to talk more openly about



Ms Jo-Anne Dobson
Motion: Crisis in Waiting Times

dying, death and bereavement, and to make plans for the end of life.

We would:

- Introduce a dignity charter across each of the Health and Social Care Trusts so that patients are at the centre of their care and decision making process;
- Ensure the full implementation of the current palliative and end of life programmes;
- Ensure doctors identify patients who are dying in order to support the wishes of those would prefer to end their life at home;
- Promote the use of Advance Care Planning;
- Centrally collate the data regarding care being offered to people approaching the end of their life and survey patients, families and carers to assess how the local system met the needs of people with a terminal illness.



Unionist
Ulster Unionist Party

Doing what's right for Northern Ireland



Ulster Unionist Party

Strandtown Hall

2-4 Belmont Road

Belfast

BT4 2AN

Tel: 02890 474630

www.uup.org