

# BEATING CANCER: AMBITION AND ACTION

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The Scottish Government  
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# 1. BEATING CANCER: AMBITION AND ACTION



**Shona Robison**  
Cabinet Secretary

*Shona Robison*

we have made in fighting cancer over the last 10 years.

Action to reduce health inequalities and to provide person-centred care are both central to delivery of this Strategy.

From initial tests through to diagnosis and treatment, having cancer can be a scary, difficult place. We need to support people who use services to have their voices heard and to support health and care services to listen, learn and improve to deliver more person-centred care.

We know that to reduce health inequalities we need to ensure people have sufficient knowledge, understanding, confidence and skills to cope with the complex demands of modern health care.

This strategy sets out our ambitions on improving the prevention, detection, diagnosis, treatment and after care for people affected by cancer.

Through this strategy we will outline new actions we will take and also reflect and learn from the progress

People are at the heart of this strategy, guided by the over-riding principle that everyone must have access to the services and to information they need to make the right choices for them and their families.

We have identified at least £100 million of additional investment over 5 years to help make this strategy a reality.

This strategy embeds our actions on detecting cancer early, not least through screening programmes. It sets out how we will invest in the provision of good quality, sustainable treatment and support for people to live well with, and beyond, cancer.

A key element to the strategy is on the measures in place, and the further plans being developed, to reduce the risk of people getting cancer in the first place.

All of this work is underpinned by measures to improve the quality and timeliness of data, and research and support to ensure we have a workforce with the right skills to tackle cancer in Scotland.

Our ambition is to shape the delivery of this strategy over the next decade by working together with people with cancer, their representatives, clinicians and service providers to reduce the impact of cancer and achieve world-class cancer outcomes for the people of Scotland.

## THE CHALLENGE

Two out of five people will develop cancer in their lifetime.

32,000 people in Scotland were diagnosed with cancer in 2013 – an increase of around 12% in a decade. By 2027 this is expected to reach 40,000 a year – 110 people being diagnosed with cancer every day.

The number of people diagnosed will continue to rise. This is due, not least, to our ageing population and our success in increasing survival rates from other diseases.

With effective population-based screening programmes, earlier detection, better diagnostic methods and advances in treatments, more people in Scotland are surviving cancer than ever before. Cancer mortality rates in Scotland have reduced by 11% over the last 10 years.

We know that health inequalities are the result of fundamental inequity in the distribution of power, money and resources. This has an impact on the opportunities for good quality work, education and housing. In turn, these determinants shape individual experiences and health throughout life.

Cancer incidence is more common in the most deprived areas of Scotland – incidence rates have typically been 30% to 50% higher in the most deprived compared to the least deprived areas. Health inequalities can also be found in cancer mortality rates. Of people in the 45 to 74 year age group, those living in most deprived areas are more than twice as likely to die of cancer than those in the least deprived areas.

There are a number of reasons for this including lifestyle choices, variations in screening uptake and later diagnosis which

ultimately have an impact on cancer survival. This situation is not inevitable and can be improved.

For people diagnosed with cancer between 1987 and 2011 the one-year survival rates have increased in men from 48% to 66%, and in women from 58 % to 69%. Five-year survival rates have increased from 29% to 48% in men, and from 40% to 54% in women.

This increase in the number of people surviving cancer will result in an increased use of specialist and primary care services, and due to the increasing age-profile, people using these services will most likely be presenting with multiple health conditions and complex health needs.

A key challenge will be for health, social care and third sector services to develop sustainable and innovative approaches to cancer care which meet the changing requirements of people with cancer to support them to live healthy lives at home.

But we can only rise to this challenge if we are willing to be ambitious in the change that can be realised.

## REALISING OUR AMBITIONS

We will improve the experience of and outcomes for people affected by cancer across Scotland by improving service delivery and reducing health inequalities. We will do this by building on our extensive prevention programme already in place, in line with our 2020 vision for safe, effective, person-centred care and the National Clinical Strategy.

Fundamentally, the person-centred approach means asking not: “What’s the matter with you?”, but: “What matters to you?” and not assuming we know the answer in advance. It means finding out who is important to the

person, and working with the individual and their loved ones to support their choices and their care. It means providing the information people need to be fully involved in decision making, ensuring that services and other support are as far as possible organised around their needs, and enabling them to be involved in decisions about their care at the level that makes sense to them.

We will place people with cancer at the centre of their care ensuring they are partners in their care able to make informed choices and know what is happening when and why. Feedback from individuals is vital for the continual evolution of cancer services and care, which is why we will ensure that the Scottish Cancer Patient Experience Survey is implemented and taken forward on a regular basis.

We will drive forward work to support early cancer diagnosis through uptake of national screening programmes and improved diagnostic capacity, with work focused on hard-to-reach groups. We are committed to continuing the Detect Cancer Early programme, including for breast, lung and bowel cancers. We will build on the programme to raise public awareness of potential risk factors for developing cancer, symptoms to be aware of, and of the availability and information on screening to increase uptake.

We will act on health inequalities in cancer outcomes by taking action to help more equitable access to screening, earlier diagnosis, support for health literacy and access to services to support people who are living with cancer that are aimed directly at hard-to-reach groups.

We will improve access to sustainable, high quality, effective cancer treatments across Scotland. Where someone has been diagnosed

with cancer we want them to have access to the best professional and clinical support and services. Through workforce planning we want to ensure that everyone with cancer in Scotland who needs it has access to a specialist nurse during their care and treatment.

We will ensure people living with and beyond cancer have the support they need to live and, when the time comes, die well.

To make certain treatments and care is rooted in evidence we will work to improve the data we collect, analyse and publish, to better reflect the experiences of people with cancer. We want to embed research in the ethos of our healthcare services – allowing individuals access to and participation in clinical trials appropriate to their circumstances.

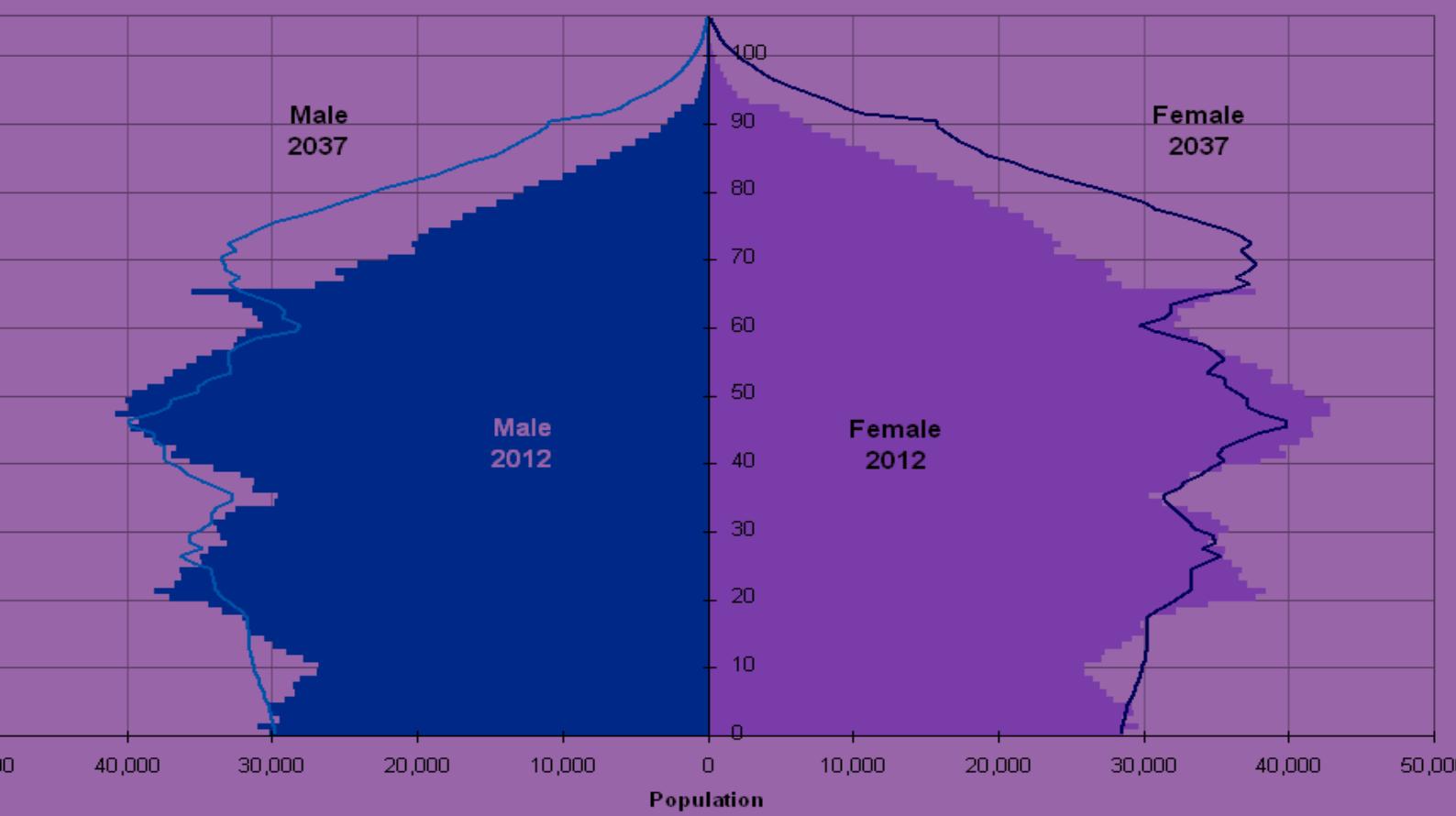
We will underpin and support this work by establishing a new cancer intelligence system to provide high quality, timely information for clinicians and individuals at all stages of their cancer journey, and by funding vital research.

## WHAT WOULD SUCCESS LOOK LIKE?



- More people surviving cancer for 1, 5 and 10 years
- Closing the gap in survival rates between Scotland and the best countries in Europe
- A reduction in cancer health inequalities
- People with cancer and their families feeling involved in decision making and able to make the right decisions for them on the basis of full information
- A radical improvement in experience and quality of life, including at the end of life
- A reduction in the growth in the number of people diagnosed with cancer
- More equitable access to services and treatment

# 2. SCOTLAND IS CHANGING – OUR SERVICES MUST CHANGE WITH IT



## 2. SCOTLAND IS CHANGING – OUR SERVICES MUST CHANGE WITH IT

Scotland's population is changing and this will have an inevitable impact on the demand for health and social care, including cancer services. By 2039, the number of people in Scotland aged 65 or over is expected to increase by 53% to 1.5 million people and the number of households headed by people in this age group is set to increase by 54% to almost 1 million by 2037.<sup>1</sup> This is good news, but means we must plan to meet the increasing demands on our health and care services through the growth, nature, complexity and acuity of the disease being faced.

Although there is much to celebrate in the significant improvements that have been made in improving mortality and survival rates from cancer in recent years, the incidence of cancer continues to increase.

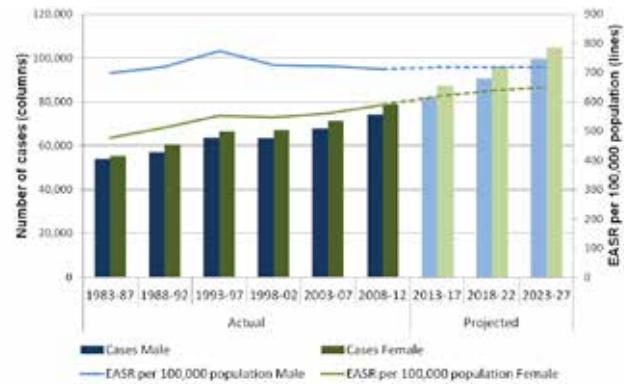
This presents new challenges that we, as a cancer community, must address in order to drive forward further service improvement and help reduce inequities in cancer care.

Over 40% of people in Scotland will be diagnosed with cancer during their lifetime. Around 1 in 13 men and 1 in 9 women will develop cancer before the age of 65.<sup>2</sup> The number of people being diagnosed with cancer continues to increase.

Around 32,000 people in Scotland were diagnosed with cancer in 2013, an increase of around 12% since 2003 and is expected to reach 40,000 diagnoses by 2023-27.<sup>3</sup> Approximately half of these diagnoses will be of the most common cancers: lung, breast, prostate and colorectal and the other half will be less common or rare cancers.

The rise in the number of diagnoses is due partly to the ageing population as a result of our successes in treating the most common killer diseases such as coronary heart disease and stroke as well as cancer. But it is also driven by changes in lifestyles.

**Chart 1 – All cancers (excluding non-melanoma skin cancer). Number of new cases and EASR per 100,000 population; 1983-87 to 2023-27<sup>4</sup>**

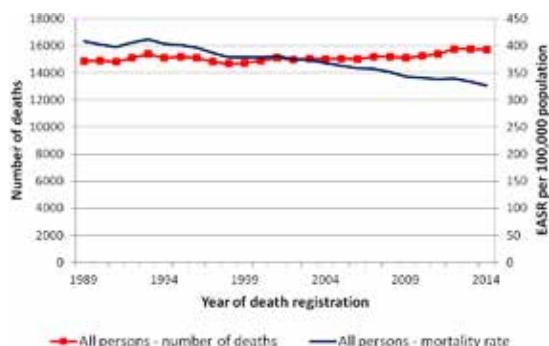


Source: Scottish Cancer Registry, National Records of Scotland, NORDPRED<sup>5</sup>

There is considerable variation across different types of cancer and this will have an impact on the nature of demand for services. For instance, the incidence rate of malignant melanoma of the skin has increased by 30% over the last 10 years. In contrast, the incidence rate of cancer of the oesophagus has decreased by 8% over the same period. Lung cancer is predicted to continue to be the most common cancer in 2023-27.

Cancer mortality rates in Scotland have reduced by 11% over the last 10 years.<sup>6</sup> This reflects the progress made in the prevention, early detection and treatment of cancer. But the number of deaths due to cancer has remained constant which reflects an increase in older age groups within the population and the fact that cancer is a relatively common disease among the elderly.

### **Chart 2 - Cancer<sup>7</sup> mortality in Scotland, 1989-2014. Number of deaths and age-standardised mortality rate<sup>8</sup>**



Source: National Records of Scotland<sup>9</sup>

There is more to be done and in particular addressing the variation in mortality between men and women and certain tumour types. One of the keys to improving mortality rates is earlier diagnosis and treatment and the actions in this strategy build on our progress in improving screening rates and early detection.

Despite these improvements in mortality rates, in 2014, 15,746 people died from cancer in Scotland. Lung cancer accounts for the greatest number of deaths (26% of all cancers), followed by colorectal (10%), breast (6%) and prostate (6%).<sup>10</sup>

There is, however, good news. More people than ever before are surviving after cancer. People who were diagnosed with cancer between 1987 and 2011 have seen one-year survival rates increased in men from 48% to

66% and in women from 58% to 69%. Five-year survival rates have increased from 29% to 48% in men and from 40% to 54% in women. This increase is reported for most cancers with large advances in some tumour types, such as prostate, multiple myeloma, Non-Hodgkin's lymphoma, kidney cancer, leukaemia and female breast cancer.<sup>11</sup>

Health inequalities across Scotland mean that cancer incidence is more common in the most deprived areas of Scotland – incidence rates have typically been 30% to 50% higher in the most deprived compared to the least deprived areas. There are a number of reasons for this including lifestyle choices and variations in screening uptake which ultimately have an impact on cancer survival for some types of cancer. Health inequalities can also be found in cancer mortality rates. Of people in the 45 to 74 year age group, those living in most deprived areas are more than twice as likely to die of cancer than those in the least deprived areas.

Some of the most common types of cancer, where the gap between the most and least deprived areas is largest, are cancer of the trachea, bronchus and lung, mirroring the socially patterned smoking rates. Mortality rates show a similar picture. The gap between least and most deprived areas is projected to continue to widen and action therefore needs to be taken to reverse this.

### **CANCER AND HEALTHY LIFE EXPECTANCY**

We also know that surviving after cancer is not always the same as living a full and healthy life. There can be long-term consequences of treatment that require ongoing care and support.

People who have been diagnosed with cancer have a greater risk of being diagnosed with cancer again in the future, and on some

occasions people treated for a primary cancer will also develop secondary or metastatic cancer, which may be treatable although incurable. People may live for many years after cancer and should receive the treatment and support they need to live for as long and as well as possible at home, managing their cancer effectively as a long-term condition.

The experience and quality of life that people with cancer have through and beyond diagnosis and treatment is equally as important as clinical effectiveness and safety. It is therefore essential that we strive to deliver cancer care in ways to ensure that people receive the support they need to live as long and healthy a life as possible.

As the majority of people diagnosed with cancer are over the age of 65, many may already have multiple morbidities – it is estimated that 70% of people with cancer have at least one other long-term condition that needs managing and over a quarter have at least three other such conditions.<sup>12</sup>

# 3. PREVENTION



### 3. PREVENTION

#### Our Ambitions

**To encourage and support people to reduce their risk of cancer by living healthier lives, focusing on reducing health inequalities.**

**To create a generation of young people who do not want to smoke, with aim of reducing smoking prevalence to 5% or less by 2034.**

**To reduce alcohol-related harm by helping to prevent problems arising in the first place.**

**To make it easier for people to be more active, to eat less, and to eat better.**

**To help more people be more active more often.**

**To help people make healthier choices to reduce their exposure to UV radiation.**

There is strong evidence that smoking, alcohol consumption, physical inactivity, diet and obesity are risk factors for many health conditions, including cancer.<sup>13</sup> By encouraging and supporting people to live healthier lives, be more active and improve their diet we can reduce the risk of many individuals not only for cancer but a range of other conditions such as heart disease and stroke.

Our positive health promotion activity on tobacco, alcohol, diet and physical exercise is already working to improve the health of Scotland's population as a whole and we expect that this will have a consequent long-term positive effect on reducing the risk of cancer. We need to better understand whether and how to focus activity to reduce health inequalities.

Evidence suggests that concern about single diseases may be greater, and more motivating, than of collective diseases in general. In particular, it is clear that despite widespread public awareness of the health risks associated

with unhealthy lifestyles, the population does not appear to explicitly link this with cancer causation.<sup>14</sup>

Through the implementation and development of our public health initiatives, we will work to change this perception and shift cultural attitudes towards cancer risk factors including smoking, poor diet, physical inactivity and alcohol consumption. Through this strategy we will explore how the 'Act Well' programme can be further piloted on a larger scale.

The rising incidence of melanoma in Scotland indicates the need for continued efforts to raise awareness of the risks associated with unsafe tanning. This increase also poses challenges for dermatology services who will need to adapt to meet this increasing demand.

#### TOBACCO CONTROL

Smoking is the primary preventable cause of ill-health and premature death. Each year, tobacco use is associated with 128,000

smoking attributable hospital admissions and 10,000 smoking attributable deaths per year in Scotland - a fifth of all deaths.

Smoking remains one of the principal causes of illness and premature death in Scotland and is strongly associated with a range of cancers.

Cancer of the trachea, bronchus and lung is significantly more prevalent in the most deprived areas, mirroring the socially patterned smoking rates. Scotland has amongst the highest incidence rates and lowest survival rates from lung cancer in Europe and there are clear links with historic smoking rates.<sup>15,16,17</sup>

The 2014 Scottish Household Survey showed that 20% of adults smoke - a drop of 3 percentage points on the previous 3 years and the sharpest year-to-year decline in smoking rates since the survey began in 1999. Encouragingly, the sharpest decline in smoking rates is in the most deprived areas which dropped from 39% in 2013 to 34% in 2014.

## **ALCOHOL**

We know that, as well as many other harms, alcohol has a significant causal role in cancers such as breast, liver, bowel, mouth and throat, and so we have taken bold action to tackle and reduce the damage it causes through our alcohol strategy, *Changing Scotland's Relationship with Alcohol: A Framework for Action*.<sup>18</sup> We have placed a whole population approach at the heart of our Alcohol Framework which includes a package of over 40 measures to reduce alcohol-related harm by helping to prevent problems arising in the first place, and includes improving support and treatment for those who are already experiencing problems.

We know that drinkers living in the most deprived areas suffer greater harms than

drinkers living in the least deprived areas. Tackling alcohol-related harm through minimum unit pricing of alcohol has the potential to significantly reduce health inequalities.

Considerable progress has been made on implementing key aspects of the Framework including:

- a record investment in tackling alcohol misuse of over £319 million since 2008;
- delivery of over 569,000 alcohol brief interventions by NHSScotland;
- establishment of 30 Alcohol and Drug Partnerships;
- introduction of the quantity discount ban;
- improved substance misuse education;
- passing of minimum unit pricing legislation; and
- introduction of lower drink-drive limit.

We have seen some improvements in harm levels in recent years and the Framework has been shown to have a positive impact. However, harm levels are still higher than they have been in previous decades. New lower-risk drinking guidelines were issued by the Chief Medical Officers in January 2016<sup>19</sup> following a review of the scientific evidence on the short and long term impact on health from alcohol.

The evidence which has emerged since the previous guidelines were issued in 1995 suggests that there are adverse effects on a range of cancers from drinking alcohol and these risks start from any level of regular drinking and then rise with the amounts of alcohol being consumed. This is consistent with the International Agency for Research on Cancer's World Cancer Report 2014<sup>20</sup> and the Canadian Cancer Society which state that there is no "safe limit" of alcohol consumption when it comes to cancer prevention.

## **DIET AND OBESITY**

We can lower our risk of developing certain cancers by eating a healthy balanced diet that is low in fat (especially saturated fat), salt and sugar, with plenty of fruit and vegetables and starchy foods, choosing wholegrain versions when we can.

In addition to those nutrients associated with increased risks of overweight and obesity, Cancer Research UK estimate that more than 30,000 cancer deaths could be prevented by adopting a healthy diet, in particular, through an increase in fruit, vegetable and fibre consumption, limiting red and processed meat and reducing sugar and salt.<sup>21</sup>

To improve diet we have invested over £10 million in the four years to 2016 in projects to encourage healthy eating. With the assistance of Food Standards Scotland, we are also engaging with the food and drink industry through our Supporting Healthy Choices Voluntary Framework,<sup>22</sup> to support consumers to make healthier choices and press for action to reduce sugar intake. Key areas for action are around labelling, rebalancing promotions, responsible marketing of food and drink and reformulation of products, including a focus to reduce calories, salt, fats and added sugar in foods.

Poor diet is often associated with people on lower incomes, the most deprived consume less fibre and fruit and vegetables, and more sugar than the most affluent. We continue therefore to support Community Food and Health (Scotland)<sup>23, 24</sup> to help build capacity in the community food sector at a national level. In addition, we provide core support to established community food networks to help them give healthy eating assistance to those most vulnerable groups in society.

Food Standards Scotland (FSS) have made recommendations to Scottish Ministers on further action to support healthier diets in Scotland. We will consider these recommendations, which support a whole government approach, the food and drink industry, and the public sector, with a view to building on our current programmes of work to accelerate progress.

We have recently accepted FSS recommendations to revise the Scottish Dietary Goals for sugar and fibre as well as agree a new goal for total carbohydrates.<sup>25</sup> The scale of the health inequalities problem is strongly influenced by the magnitude of the underlying inequalities in power, money and resources within a society. Action on the worsening trends in health inequalities needs to be rebalanced to address the fundamental drivers of social inequality which determine income, employment, education and daily living conditions.

## **PHYSICAL ACTIVITY**

Taking part in physical activity is recognised to lead to a wide range of benefits, not least to individual health. UK Chief Medical Officers have issued joint guidelines to explain these benefits.<sup>26</sup>

The Active Scotland Outcomes Framework<sup>27</sup> describes Scotland's ambitions for sport and physical activity over the next 10 years. Success will rely on the collective efforts of communities, individuals and a wide range of partners. Key evidence informing progress towards the outcomes is available at the link above. The headline measure of progress is the proportion of the population who meet the recommended level of physical activity. This is a National Indicator.

The Active Scotland Outcomes Framework is underpinned by a commitment to equality. An analysis of equality data across the indicators has been carried out and to provide a baseline from which progress can be monitored.<sup>28</sup> To achieve the vision, a transformational change programme of actions is ongoing. The work is overseen by the National Strategic Group for Sport and Physical Activity (NSG), chaired by the Cabinet Secretary for Health, Wellbeing and Sport.

It includes:

- Implementation of the National Walking Strategy<sup>29</sup> and the Cycling Action Plan.<sup>30</sup> This work is supported by £58 million committed to walking and cycling projects.
- Investing £500,000 annually to support *Active Girls*<sup>31</sup> which aims to increase the number of teenage girls participating in PE, physical activity and sport in and around schools.
- Working towards the establishment of 150 Community Sport Hubs across all local authorities by 2016, with 50% based in schools.
- Awards to a total of 188 projects across all 32 local authorities from the £10 million *Legacy 2014 Active Places Fund*<sup>32</sup> to help enable communities to build, upgrade and improve facilities to drive participation in sport and physical activity.
- Continuing to invest £1.6 million of legacy funding to maintain momentum and continue to capitalise on the inspiration that the Commonwealth Games have provided. £800,000 of this is being used for the *Legacy 2014 Physical Activity Fund*,<sup>33</sup> aimed at building on current good practice at local level and scaling this up to impact on many more people, with a particular focus on inactive groups.

## UV EXPOSURE

There are a number of simple actions that people can take to reduce their exposure to UV radiation, but there is also a continuing need to support people in making healthier choices in relation to sunbeds.

Education and awareness of lifestyle choices and behaviours should begin in childhood. Through our Detect Cancer Early programme we have supported the development of Teenage Cancer Trust's schools-based education programme. The education programme provides young people with the information on lifestyle choices, common signs and symptoms to be aware of and encourages them to discuss cancer prevention and awareness with older family members.

Breaking down barriers and getting people to talk about cancer is an important part of the Detect Cancer Early programme and the longer-term opportunities are exciting as young people become more at ease discussing cancer and take with them an increased awareness, knowledge and understanding of cancer into their adult lives, resulting in a change in presentation behaviour, earlier diagnosis and improved survival chances.

Ultraviolet radiation (UV) exposure is the primary recognised risk factor linked to malignant melanoma of the skin. It is now the sixth most common cancer in men and the fifth most common in women. The increase in the number of people being diagnosed with malignant melanoma may in part be due to better public awareness and improved diagnosis, however, continued action is important to ensure that malignant melanoma is prevented where possible.

Scotland was the first part of the UK to introduce legislation to address the health risks associated with sunbed use. The Public

Health etc. (Scotland) Act 2008 Sunbed Regulations (Scotland) 2009<sup>34</sup> prohibits the use of sunbeds by under 18s; requires operators to supervise the use of sunbeds; places a duty upon the operator of sunbed premises to display a public information notice; and requires operators to provide customers with health information on the health risks associated with sunbed use.

## OCCUPATIONAL EXPOSURE

Some people may have an increased risk of cancer because they used to work with cancer-causing substances before more recent regulations came into force. It is estimated that occupational exposure to cancer-causing chemicals is responsible for nearly 4% of cancer cases in the UK.<sup>35</sup>

These exposures are now less of a problem as the most dangerous chemicals have been banned for several decades, and employers are now legally required to prevent and control exposure to chemicals that may cause cancer.

Occupational health and safety is a reserved matter; with responsibility for enforcement of occupational hygiene standards and control of occupational hazards residing with the Health and Safety Executive who enforce standards across the UK.

In Scotland, HSE works within the health policy delivery model and with different, uniquely Scottish delivery organisations along with the support of the Partnership on Health and Safety in Scotland (PHASS). We will continue to do this with relevant stakeholders to consider evidence of links between work and cancers. We will work with a wide range of partners including the HSE, local government, trades unions and employers' bodies through the Partnership on Health and Safety in Scotland (PHASS) to support safe

and healthy workplaces, and to understand the evidence on links between work and cancers.

## HPV VACCINATION

Immunisation has a role to play in preventing a number of cancers. The Scottish Government takes its advice on immunisation from the Joint Committee on Vaccination and Immunisation (JCVI).

In 2008 we introduced an HPV vaccination programme to protect girls against cervical cancer. Uptake of this programme has been extremely high, and investigations are underway to determine the feasibility of testing women for the presence of HPV in the first instance which will mean that many women may not have to undergo a cervical 'smear' test.

The JCVI recently recommended the expansion of the HPV vaccination programme to Men who have sex with Men (MSM); to the HIV positive population and to a number of other groups to protect against a range of cancers. We are currently investigating how this can be taken forward in Scotland.

The JCVI is also investigating a gender neutral programme for the HPV vaccine, to establish whether it would be advisable for boys to be vaccinated as well as girls.<sup>36</sup>

## HEALTH PROMOTING HEALTH SERVICE (HPHS)

Evidence shows that people from deprived communities are more likely to have poorer health outcomes and they also use acute services more than the population as a whole. The HPHS ethos provides an opportunity to address inequalities and we are supporting NHS Boards to ensure that routine enquiry for vulnerability is built into person-centred care and, therefore, those at risk of poverty and inequality attain the best possible health outcomes.

The vision for a Health Promoting Health Service (HPHS) is a cultural transformation, one which ensures that every healthcare contact is maximised and a health improvement opportunity. Although this ethos applies to individuals and visitors, the promotion of staff health and wellbeing is equally central to the HPHS vision.

NHSScotland has a key responsibility for promoting health and wellbeing within the population it serves. It has a leading role as a public service, as a healthcare organisation, as a major employer and as a partner to other organisations that have a mutual interest in population health.

This requires that all hospital settings embed specific actions that promote health improvement. This need has been communicated over the last few years through a series of letters from the Scottish Government to Board Chief Executives. The latest letter, CMO (2015) 19,<sup>37</sup> Health Promoting Health Service: Action in Secondary Care Settings, was issued on 9 October 2015, from the Chief Medical Officer (CMO) for Scotland.

Clinical buy-in and leadership is paramount to ensure that health improvement is prioritised. To this end we will encourage and support clinical staff in screening services to maximise opportunities to deliver health improvement messages with the proviso that appropriate onward referral pathways are available for staff to refer individuals.

## **Actions – Prevention**

- We will ensure all the actions in our *Tobacco Control Strategy, Creating a Tobacco Free Generation*<sup>38</sup> are implemented in full. This focusses on reducing the health inequalities inherent in smoking; creating an environment that supports young people to choose not to take up smoking; continuing to protect people from second-hand smoke; and supporting smokers to quit.
- We will continue to task health boards to deliver a higher proportion of successful smoking quits from the most deprived areas, and to increase that proportion in future years.
- We will explore how initiatives like the ‘Act Well’ programme, (a personalised breast cancer risk reduction programme offered to women attending routine breast screening clinics) can be fully tested for effectiveness and roll out. If proven effective we will invest up to £1m over four years to offer similar opportunities in a wider range of NHS Boards.
- Through the next phase of the Alcohol Framework we will highlight the potential causal links between excessive alcohol consumption and the risk of cancer.
- We will undertake a review of the *Preventing Overweight and Obesity in Scotland: A Route Map Towards Healthy Weight*<sup>39</sup> to ensure that it is reflecting the best available advice, including on cancer risks, and practice into the future.
- Through our Detect Cancer Early programme we will continue to work in partnership with Teenage Cancer Trust to roll out their schools based education and awareness programmes. This will help ensure young people across Scotland have access to cancer prevention and early detection messages. We will highlight in particular the links between unsafe tanning and cancer to help protect those who are most vulnerable - the young and impressionable.

# 4. IMPROVING SURVIVAL



## 4. IMPROVING SURVIVAL

### Our Ambitions

**To improve cancer survival to a level at least equivalent to other UK and European countries.**

**To reduce variation in survival rates among the least affluent and most affluent areas across Scotland.**

**To reduce variation as much as is possible in survival rates in different types of cancer.**

**To empower people to make balanced and informed decisions around participation in national cancer screening programmes.**

**To stop anyone dying from breast cancer by 2050, a shared ambition with Breast Cancer Now.**

We know that participating in the national population cancer screening programmes is one of the best ways to detect cancer early and to help reduce health inequalities in cancer.

We have three well-established and successful population screening programmes for breast, bowel and cervical cancer. The last of these plays an active part in preventing cancer in the first place. Breast and bowel screening both have a significant role in identifying cancer at an early stage which improves the chances of survival.

Improving our ability to detect cancer at an early stage will make a significant contribution towards achieving our ambition of increasing survival from cancer and in reducing variation in survival rates across Scotland.

Stage of diagnosis, as a proxy indicator for survival, shows that for the three most common cancers in Scotland (breast, lung and

colorectal) there is a correlation between later stage presentation and increased deprivation.

Through the Detect Cancer Early programme (DCE) we are already raising awareness of the benefits of screening programmes and improving information available for people to make informed decisions about screening programme participation.

Building on this progress we will further develop a new approach to better understand and tackle inequalities of access to screening services. This will focus on stronger strategic goals and actions, supported by partnerships and effective local delivery in order to change perceptions and attitudes to cancer in Scotland in a bid to reduce fear around the disease and encourage earlier presentation.

## NATIONAL POPULATION CANCER SCREENING PROGRAMMES

The UK National Screening Committee (NSC)<sup>40</sup> is a body of independent experts who advise the NHS and Governments across the UK on screening policy. NSC will also provide advice in the area of genetic screening and to consider risk stratification within new and existing screening programmes.

Any new screening programmes are subjected to the rigorous criteria set out by the NSC before being implemented in Scotland.

The Scottish Standing Committee for national screening programmes, which will start work during 2016, will carefully consider NSC recommendations and provide advice to ensure recommendations and decisions are taken in the context of the challenges facing the NHS in Scotland.

Sharing national data plays an important role in encouraging improvement of inequalities of access to screening programmes in local areas. Our successful focus on improved access and use of data on inequalities to identify new ways to ensure equal uptake of screening will continue to underpin DCE.

We understand that a national approach cannot fully address the diverse needs of the population, and so we will continue to encourage local initiatives and provide Health Boards with the tools to measure the effect of interventions looking to support further expansion where possible.

The third sector provides valuable support and information to those who engage with the national population cancer screening programmes. Their role is also important to work within the screening programmes in identifying and engaging with hard-to-reach communities.

## NATIONAL BREAST SCREENING PROGRAMME

In Scotland, women between the ages of 50 to 70 are invited for breast screening every 3 years. Since 2010, all attendances for breast screening consist of two mammograms taken from different views.

The extension of the ages of women screened from 64 to 70 in 2003 and the subsequent introduction of two mammograms being taken at each screening appointment have contributed to the increased detection of cancer.<sup>41</sup>

## NATIONAL BOWEL SCREENING PROGRAMME

Over the past few years we have seen considerable progress in relation to bowel screening. All men and women registered with a Community Health Index (CHI) number and aged between 50 to 74 years are invited to participate and to be screened every 2 years. Those aged 75 or over are able to self-refer to the bowel screening programme every two years by requesting a screening kit through the Scottish Bowel Screening helpline.<sup>42</sup>

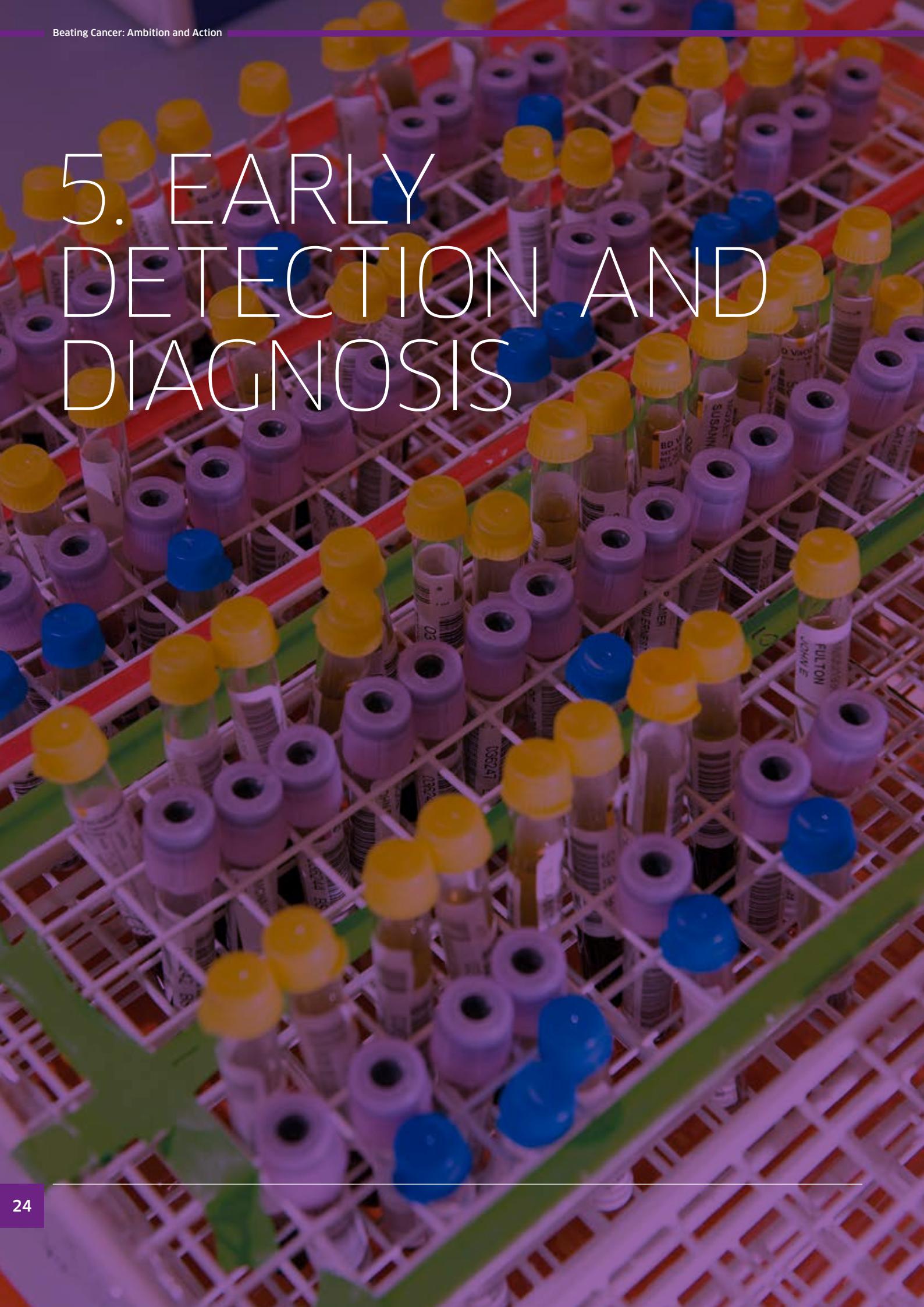
## NATIONAL CERVICAL SCREENING PROGRAMME

All women aged 20 to 60 across Scotland are currently invited to have a cervical screening test every 3 years. A set of leaflets are available to inform and enable women to make an informed choice to attend their screening appointment.<sup>43</sup>

## **Actions – Improving Survival**

- Invest up to £5 million in the next 5 years in new activity targeted to improve outcomes by addressing health inequalities, including in screening and by supporting the development of an NHSScotland network to develop innovative strategies and share learning on inequalities in screening.
- Add cervical cancer to bowel and breast through targeted public awareness campaigns in areas of higher deprivation.
- Working in partnership with organisations such as CRUK, Breast Cancer Now, Walk the Walk, Jo's Cervical Trust, and Bowel Cancer UK we will participate in projects to explore how we can best make improvements to our screening programmes.
- Complete the roll-out of digital mammography to all our breast screening centres in 2016. Due to superior imaging quality this investment in upgrading mammography screening equipment to capture digital images will further enhance our ability to detect cancers early.
- Make the current home testing for bowel screening easier from 2017. Replacing the current kit with the quantitative Faecal Immunochemical Test, or FIT. Not only is this a more sensitive test, which will increase our ability to detect cancers at the earliest stages, it is more user-friendly as it requires only a single sample to be taken. It is anticipated that its relative ease of use will encourage more people to participate in the programme.
- Examine the evidence from an ongoing trial to determine the need for a national roll-out of a flexible sigmoidoscopy one-off test that looks at the lower part of the bowel where most bowel cancers are found.
- Change the age range and frequency for cervical screening in line with the National Screening Committee recommendations.<sup>44</sup>
- Following a successful pilot, we will introduce Human Papilloma Virus HPV testing for all women who have had treatment for cervical intra-epithelial neoplasia (CIN). This will be available at their next cervical screening test. Women who have a test that shows normal cervical cells and no HPV (HPV negative) 6 months after treatment for CIN will return to routine 3-yearly screening.
- Introduce HPV testing as a first-line test in the cervical screening programme, dovetailing with the HPV vaccination programme. An expert group is currently considering a business case for the introduction of HPV testing within the programme.

# 5. EARLY DETECTION AND DIAGNOSIS



# 5. EARLY DETECTION AND DIAGNOSIS

## Our Ambitions

**To make early detection of cancer the norm.**

**To have swift diagnosis and results for clinicians and individuals.**

**To enhance the role of primary care in beating cancer.**

Improving our ability to detect cancer at an early stage will make a significant difference towards achieving our ambition of increasing survival from cancer and in reducing variation in survival rates across Scotland.

Five-year survival rates from cancer in Scotland are lower than other European countries. This difference occurs mostly in the first year after diagnosis, suggesting that advanced stage at disease presentation could contribute to this survival difference.

Diagnosing cancer earlier will often improve quality of life after treatment. For those with advanced disease it can mean that individuals may still be well enough to tolerate treatments that could slow down progression of the disease and prolong life.

Some people also miss the opportunity to join clinical trials because they are often not well enough to participate at the point they are diagnosed. Earlier diagnosis will enable more people to join clinical trials which are recognised as improving outcomes and to support the development of new and effective treatments.

Changing public perceptions and attitudes to cancer will take time, however, through

targeting public awareness messaging to those most likely to present with later stage disease and those less likely to participate in screening (those living in the more deprived communities across Scotland) improvements in outcomes can be achieved.

Short-lived early detection programmes alone are unlikely to eradicate Scotland's cancer survival deficit, or fully address the cancer health inequalities gap. By sustaining efforts targeted at earlier stage detection, we will help achieve our ambition of improving survival rates.

### **DETECT CANCER EARLY PROGRAMME (DCE)**

The Scottish Government has invested £39 million in the DCE programme since February 2012.<sup>45</sup> This ambitious programme aims to improve 1-year and 5-year survival rates for people with cancer in Scotland by actively addressing diagnoses and treatment at an early stage.

The programme also aims to reduce differences in cancer survival rates between the most affluent and least affluent areas of Scotland. There are five DCE work streams:

- Public Awareness

- Informed decision making around screening programme participation
- Primary Care recognition and referral behaviour
- Increasing Diagnostic Capacity
- Data, Evaluation and Outcomes

## PUBLIC AWARENESS

DCE campaigns are particularly targeted to those living in the more deprived communities empowering individuals to recognise early signs of cancer and balance the value of screening programme participation. This ensures that those more likely to present with later stage disease and those who have poorer outcomes following a cancer diagnosis are particularly targeted. The ‘influencers’ (friends/family members) of this audience are also key to the social marketing activity.

Successful DCE social marketing campaigns have taken place in breast, lung and colorectal cancer. All marketing activity is extensively tested and is delivered in collaboration with local NHS Board public health departments to engage with the most hard to reach groups, this marketing included targeted television buying, local radio platforms, innovative use of social media and field activity in high footfall areas such as football matches and shopping centres.

As we develop the DCE programme we will continue to take forward our work on detection of breast, lung and bowel cancer as we build for the future.

We will continue to target these campaigns to those living in the most deprived areas to reduce the variation in survival rates between the least and most affluent communities.

## THE ‘WEE C’

A new strand of activity was introduced into the DCE programme in 2015 – the ‘wee c’. In partnership with Cancer Research UK, the ‘wee c’ aims to change perceptions and attitudes to cancer in Scotland in a bid to reduce fear around the disease and encourage earlier presentation. This was accompanied by a generic awareness raising campaign #getchecked.<sup>46</sup>

Working in partnership we are exploring the barriers to help-seeking behaviour and, where appropriate, using and adapting the creative material developed in the programme to address these barriers and extend the reach of the programme, regularly monitoring and evaluating the impact. We will continue with our programme of early detection and support local tests of change for introducing additional tumour groups into the programme, and as a result of options appraisal, begin with malignant melanoma in 2016-17. Expansion to national activity will be considered following evaluation of local tests of change.

## ENGAGEMENT WITH PRIMARY CARE

As the DCE programme encourages people to visit their GP when they find any unusual or persistent changes to their body or health, working with GPs to promote referral or investigation at the earliest reasonable opportunity to improve cancer outcomes is vital.

The DCE programme has already supported eHealth improvements around notification of bowel screening status to primary care clinicians, and introduced initiatives to facilitate informed and timely discussions with individuals about bowel screening programme participation.

To support GPs to refer people with suspected cancer as early as possible Healthcare

Improvement Scotland, funded by DCE, led a review of the *Scottish Referral Guidelines for Suspected Cancer*.<sup>47</sup> Published in 2014, these guidelines will help GPs to identify people who are most likely to have cancer and who therefore require urgent assessment by a specialist. By providing up-to-date guidance around signs and symptoms of cancers where early detection can play a critical role we can increase the potential for successful treatment.

The DCE programme is encouraging referral activity that is aligned with the published national guidelines but allows flexibility for clinical suspicion, developing a national framework and promoting local implementation of pathways that accelerate triaged investigation and decision making for people presenting with non-specific symptoms that could indicate cancer.

There is a pilot underway in NHS Tayside looking at the use of faecal immunochemical testing (qFIT) in primary care for symptomatic individuals who may (or may not) have bowel cancer. This pilot enables GPs to identify those individuals who warrant urgent 'straight to test' referral and to reassure those in whom a policy of watch and wait would be the optimal choice.

If this pilot is successful it could transform the management of people with colorectal symptoms so that many would be spared unnecessary invasive investigation and those who need it would need it more promptly. As a consequence of the use of qFIT in routine use in primary care this may also lead to reduced waiting times. This pilot will be evaluated on completion.

## DATA, OUTCOMES AND EVALUATION

Since the launch of the DCE programme there has been a 6.5% increase in recorded early stage diagnosis for breast, lung and colorectal cancers combined.<sup>48</sup> The programme is particularly focused on reducing inequalities and has seen the largest increase in stage I diagnoses in the most deprived areas of Scotland, this is a 14% overall increase from baseline.<sup>49</sup>

There has been significant improvement in the percentage of people recorded as diagnosed with lung cancer at the earliest stage (24.7% increase) since the launch of the programme.<sup>50</sup>

There has been a 81.1% increase in the number of replacement bowel screening kits requested since the launch of the programme<sup>51</sup> and latest validated statistics from ISD also show an increase in bowel screening uptake (57.6% from 54.9%) for the period November 2012 to October 2014 compared to pre-DCE. Uptake for women was 60.3% and for men was 54.7%. In particular uptake in the most deprived areas in Scotland has increased (from 41.9% to 45.3%). Men in particular have increased from 39.6% to 43.6%).<sup>52</sup>

We are also aware of the growing demand for Dermatology services, given increasing public awareness and incidence of skin cancers. Overall, levels of demand are forecast to grow: by as much as 2.4% over the next year. Incidence of malignant melanoma is predicted to increase by 60% by 2027 (5,913 cases to 9,462 cases).<sup>53</sup>

In order to prepare the NHS for this growth and tackle existing and future demand we will work with health professionals across this service, and with appropriate representatives, to test and spread new ways of working and optimal pathways. This will embrace identified tests of change, initially on a small scale, but quickly driven and scaled up to drive more uniform service benefits.

## EARLIER DIAGNOSIS

Many people are referred by GPs and other healthcare professionals for assessment or for specific investigations to seek to identify the disease or condition that they may have. For cancer this 'symptomatic' route of referral may include a range of different investigations before a definitive diagnosis is made.

Diagnostic services have an important influence on the diagnosis of cancer and the subsequent delivery of cancer treatment. Statistics from EUROCARE studies suggest that poorer survival in Scotland primarily relates to late presentation.<sup>54</sup> Imaging plays a vital role in ensuring accurate and timely diagnosis and staging of cancer as do laboratory-based investigations. Diagnostic specialities require specific clinical expertise and specialist equipment, supported by efficient and timely mechanisms for sample collection, transport, processing, imaging, interpretation and reporting.

Significant improvements in the level of detail and discrimination in the use of imaging tests such as computed tomography (CT) and magnetic resonance imaging (MRI) have delivered the ability to detect and treat cancer at earlier stages, thus improving outcomes.

Imaging also has a significant role in assessing the effectiveness of treatment for cancer and in surveillance for recurrent disease. Modern treatment regimens which require more frequent assessment of response to treatment and an overall increase in the number of people treated has led to a requirement for significantly increased capacity to ensure timely access to CT, MRI and Positron Emission Tomography/CT (PET/CT).

We have well-developed and sophisticated diagnostic services across the country, with collaborative working to achieve equitable

access across the NHS in Scotland, supported by four national Managed Diagnostic Networks (MDNs) who focus on delivering safe and effective services, always with a focus on continuous quality improvement, in pathology, imaging, clinical biochemistry and microbiology and virology diagnostic specialities.

We also recognise that diagnostic services are subject to a range of pressures. The increasing number of older people, the growth in long-term conditions and ongoing technical and clinical developments have increased demand on all diagnostic services. It is essential that we have a clear picture of future requirements in order that we can plan effectively for the future delivery of these vital services.

The pathway to diagnosis and staging is complex and particularly so for some tumour types. Many people with symptoms and signs initially suspicious of cancer are also going through these same diagnostic (test-focused) pathways but are fortunately found not to have cancer. The demand for this wide-ranging array of tests consequently far exceeds the number of people who are subsequently found to have cancer, sometimes by as much as 100:1 and for rarer cancers an even greater ratio of demand to cancer diagnosed.

In 2015 we invested £3.7 million to fund a Regional Endoscopy Unit at Queen Margaret Hospital, Dunfermline which addresses demand by providing an additional endoscopy facility. This unit is now operational and receiving referrals from NHS Fife and NHS Lothian with plans to expand to NHS Forth Valley and NHS Tayside.

But more is needed. Currently, across Scotland, an estimated number of 223,381 scopes are provided each year for diagnostic purposes. We know that for the future we already need a further 45,000. Recent modelling suggests that demand is likely to increase by up to

20% over the next 10 years. By expanding scoping capacity across the country, we will significantly enhance facilities for the detection of cancer.

By 2021 we will have a network of six new Diagnostic and Treatment Centres across Scotland. The new centres will have a dual function of speeding up cancer diagnoses and ensuring swift access for elective procedures.

## **SUPPORTING PRIMARY CARE**

Recent information from the International Cancer Benchmarking Partnership (ICBP) suggests that some features of the interface between primary and specialist care in the UK may constrain the readiness of GPs to refer individuals, and may be important in our poorer cancer survival compared with some other countries. In particular, the study noted the difference in the availability of direct access to CT and MRI scanning for GPs.<sup>55</sup>

The Scottish Primary Care Cancer Group (SPPCG) and the Scottish Clinical Imaging Network (SCIN) have produced a Pathway paper to support and improve timely and direct access by GPs to clinical imaging for chest, abdomen and pelvis for individuals with unidentified malignancies. We are working with the SPPCG and SCIN to investigate the resource implications associated with this.

## Actions – Early Detection and Diagnosis

- We will create new processes to capture activity and waiting times' data for diagnostic tests. We will ensure this is aligned with the Innovative Health Care Delivery Programme and specifically the work to develop a transformed national cancer intelligence system.
- Invest an additional £2 million per annum in a new Diagnostics Fund to support swift access to diagnostics for people with a suspected cancer diagnosis.
- Increase MRI capacity at the Golden Jubilee National Hospital from April 2016.
- We will continue to target our Detect Cancer Early social marketing campaigns to those individuals who are most likely to present with later stage disease and less likely to participate in screening. Add malignant melanoma to the DCE programme, investing £500,000 in local tests of change throughout 2016-17 to expand DCE in this way.
- Expand the collaborative focus for dermatology, and more particularly melanoma, by harnessing the proven methodology of the successful MSK and Orthopaedics Quality Drive<sup>56</sup> and National ACCESS Programme.<sup>57</sup> This will provide a renewed focus with measurable outputs.
- Increasing by 40% the number of Nurse Endoscopists in training – who will be available for work in 2017.
- Invest an additional £1 million per annum in additional scopes capacity, which will see an additional 2,000 scopes per annum on a sustainable basis. By investing in diagnostics we aim to give people quicker access to vital cancer tests and their results.
- Participate in projects and audits with partners such as CRUK to understand and improve routes to diagnoses and ensure that any applicable lessons can be incorporated.
- Support primary care education and training in early cancer detection and screening, working collaboratively with third sector colleagues.
- Support further improvements in early diagnosis, cancer prevention and the interface between primary and secondary care. We are working in partnership with Cancer Research UK to develop and expand their health professional facilitator engagement programme across Scotland in 2016-17.

# 6. IMPROVING TREATMENT



## 6. IMPROVING TREATMENT

### Our Ambitions

**To ensure that people with cancer have equity of access to sustainable, high quality, timely treatment.**

**To reduce variation in practice/inequities in access to the most advanced treatments in accordance with individual clinical need and thereby improving outcomes.**

**To see that everyone who would benefit from it has access to advanced radiotherapy.**

**To ensure people are the lead partners in their care, able to make informed choices and know what is happening when and why.**

We know that over the coming years the demographic changes in our population will bring an increasing demand for cancer treatments which means that more people than ever before will require access to high quality cancer treatments and services that offer the best possible outcomes.

Our National Clinical Strategy makes clear our ambition that, where clinically appropriate, services should be planned and delivered at a local level. Where there is, though, evidence that better outcomes could only be reliably and sustainably produced by planning services on a regional or national level, we must look to the future and plan our services on a population basis regardless of geographical boundary.

There has been substantial investment over the years in improving cancer treatment services in Scotland. For example, since 2011, £11.5 million has been invested to improve cancer services capacity in NHS Boards, and £22 million has been invested in the Beatson West of Scotland Cancer Centre satellite radiotherapy facility at Monklands Hospital which was opened in November 2015.

We will build on that record and invest in the most appropriate services to ensure that people living with cancer have access to sustainable, high quality, person-centred treatments.

Treatment for cancer varies by tumour type, stage at diagnosis, the age (child or adult) of the person undergoing treatment as well as general health status. Treatment may involve surgery, radiotherapy, and chemotherapy (including drug therapy, hormone therapy and other agents) singly or in combination and in some instances all three modalities.

In many instances, particularly where a tumour is diagnosed at an early stage, evidence shows that cancer can be and is cured and even in some later stages people often now have many years of life to look forward to after treatment. This is illustrated in breast cancer where 5 year survival has increased substantially from 70.7% for those diagnosed between 1987 and 1991 to 88.0% for those diagnosed between 2007 and 2011.<sup>58</sup> This improvement in survival is likely to be due to a combination of factors including earlier diagnosis in women participating in

the Scottish Breast Screening programme, improvements in treatment, and better organisation and delivery of care.

It is essential that when considering what treatments to recommend, healthcare professionals involved in people's care – commonly called Multidisciplinary Teams (MDTs) – engage also with people with cancer, their carers and families, carers and their families to ensure that the treatment 'package' agreed is tailored to the person's individual circumstances so that people can get on with their everyday life as far as possible.

Evidence-based guidelines developed for people with single diseases should not necessarily be extrapolated to manage individuals with multiple conditions. This may inadvertently result in over-treatment and over-complex treatment regimens, particularly in people with cancer. This is likely to be an increasingly common issue as our population ages, but this is also a scenario that is avoidable, thus reducing potential harm.

We want to foster a culture where healthcare professionals and individuals can combine their expertise and be more comfortable in sharing the responsibility of decision making best suited to the needs of the individual.

It is important that GPs and primary care teams are also aware of, and as far as possible, involved in these discussions and conclusions as soon as practically possible to allow them to effectively support and advise people with cancer and their families while they are receiving treatment. Indeed, for people undergoing chemotherapy this relationship with the primary care team is vital and in some cases working well across Scotland as blood tests are taken by local surgeries/district nurses and relayed to relevant laboratories so that results are back before scheduled chemotherapy sessions.

There is almost certainly a role for Primary Care in follow up and monitoring of people with cancer after cancer treatment, whilst allowing rapid access to specialist care should potentially sinister symptoms recur.

Capacity within specialist cancer care to manage the essential interactions with people with cancer must be protected and facilitated by other health professionals participating in managing care and support after treatment. There are excellent examples of rural chemotherapy services delivering treatment supported by cancer centres, including services in Lochgilphead, Lorne and Islands Hospital, Western Isles Hospital, and Elgin Memorial Hospital. These services are developed in cooperation with larger centres to facilitate local access to cancer treatment.

No matter how well existing processes are working in support of people with cancer there is always more that can be done to improve their care experience. This means listening to the feedback from individuals and carers/families but it may also require system and organisational change to promote and deliver the roles and skills necessary for true person-centred care.

Such system change is articulated in models such as the House of Care,<sup>i</sup> which provides a useful representation of the components, all of which are required, to place collaborative, relational decision making and planning at the heart of person-centred.

We can and must do more to reduce inequities in cancer treatments. New processes are expected to improve access to medicines, however challenges remain in providing equitable access to high quality surgery and radiotherapy.

We know that most people diagnosed with cancer will need a combination of these

<sup>i</sup> Scotland's House of Care, information available from <https://houseofcare.wordpress.com/>.

treatments therefore we must ensure that when planning improvements in these areas, that this done in an integrated and complementary manner and that the pathway of care is as equitable as possible across Scotland.

## SURGERY

Surgery remains one of the most important treatments for cancer. NHS Boards in collaboration with the three regional cancer networks must continue to focus on ensuring that there are the right facilities, in the right location to meet the demand for surgery across all the relevant specialist surgical areas, for example urological (prostate, kidney and other urological cancers), upper gastro-intestinal/hepato-biliary cancers, bowel, breast, thoracic (lung). We have set out the projected incidence of cancers which will aid NHS Boards in understanding how the demand will impact on service needs in the coming years.

Since 2008, significant reductions in variation in surgical practice have come about through a mixture of reconfiguration of services, specialisation, peer reviews and multidisciplinary teams becoming widely embedded in day to day practice. Variations in surgical activity and outcomes still remain. For example, the appropriate selection of people requiring surgery in 2013 for upper gastrointestinal cancer was found to be as low as 24% in some NHS Boards and as high as 100% in others. Similarly, 90-day mortality for people with upper gastrointestinal cancer following surgery varied across NHS Boards between 0% and 25%.<sup>59</sup>

Evidence of this kind is crucial if we are to plan and deliver the best services possible for people with cancer. There is growing evidence that specialist surgeons practising in high-volume hospitals produce better outcomes for certain procedures. For example, a specialised

urology unit in Germany had a 5 year prostate cancer survival rate which was only slightly higher than less specialised units treating lower volumes.

The specialised centre had a rate of permanent severe incontinence of 8% that was a quarter of the rate of the other units, and a rate of impotence that was around one-third of the other units. These are serious quality of life issues that have an obvious impact on people with cancer.

Another review showed that consolidation of care resulted in an improvement in 5-year survival from 58.6% to 68.6% for all gynaecological cancers that could be staged and graded. These changes have been most marked with endometrial and ovarian cancers.<sup>60</sup> A further report considered the impact of a reconfigured regional upper gastro-intestinal cancer service. "The curative to palliative treatment ratio increased by 71%, operative morbidity fell 50%, lengths of hospital stay reduced on average by 3 days, median survival improved by 20% and overall 1-year survival improved by nearly 20%.<sup>61</sup>

Although evidence exists to support the delivery of surgery in fewer highly specialised units for some tumour groups, it should be recognised that this is not the case for all tumour types or procedures. For instance, breast cancer surgery is most often now delivered as a day case where it is possible to carry out wide local excision (lumpectomy) rather than mastectomy which was in previous years the surgery of choice.

We therefore need to carefully balance the benefits of improved outcomes achieved through maximising resources and clinical skills with increased specialisation, with the opportunities for minimally invasive or less invasive surgery delivered as locally as possible.

We are already aware of increasing pressures in urological surgery services. The National Planning Forum is currently assessing the range and type of work required to improve these services. This will be taken forward through Regional Planning Groups and will involve clinical colleagues reviewing and preparing a specific strategy for improving urological cancer pathways during 2016-17. They will also assess the requirement for additional diagnostic and surgical capacity. We are committed to looking at potential further investment, beyond what has been identified for this strategy, that may be needed so as to deliver sustainable urological surgery services for the future.

It is important to recognise that while individuals may be expected to spend time in a major centre of expertise for some highly specialist and/or complex treatment, prior to that treatment and subsequently, support should be provided locally through primary and community care and via local hospitals, across the most appropriate range of care needed, such as home visitors and telehealth services. This will help ensure that people receive the benefit of specialist expertise combined with local access.

## **NEW TECHNIQUES/TECHNOLOGY ADVANCES**

Advanced techniques such as minimally-invasive surgery and image-guided interventions are continuing to revolutionise the way we treat a significant range of tumour types and thereby speeding up recovery times and improving an individual's experience. An example of this can be seen in the advancement of laparoscopic techniques which are already improving the recovery and outcomes from cancer surgery. In 2015 we commenced a programme to introduce robotically-assisted laparoscopic surgery for prostate cancer in Scotland. This will bring benefits in terms of faster recovery, less

time spent in hospital post-surgery, better outcomes and improved quality of life.

The first robot was introduced in Aberdeen in 2015, supported by £1 million capital investment from Scottish Government. Initially this will be for the treatment of prostate cancer, where the evidence base is strongest, but in future robot-assisted minimally-invasive techniques might also be used for other indications if evidence shows that this would be beneficial.

## **RADIOTHERAPY**

Radiotherapy is an increasingly important component of modern cancer treatment and will remain so for the foreseeable future. International modelling shows that approximately half of all people with cancer would benefit from radiotherapy at some point in their treatment.<sup>62</sup> This may be given as the sole curative treatment (for example, cancer of the larynx), as part of a treatment plan incorporating surgery and/or chemotherapy for palliative purposes.

All Scottish radiotherapy departments have a comprehensive range of state-of-the-art linear accelerators and associated equipment capable of delivering the most up-to-date/technically complex treatments. £60 million has been invested in updating radiotherapy equipment in the 4 years to 2014-15. In addition to the predicted substantial rise in demand for radiotherapy, the complexity of planning and delivering these treatments is also likely to rise as the role of newer techniques becomes more clearly defined and incorporated into standard practice.

Recent advances in radiotherapy have allowed radiation doses to be targeted more precisely and therefore require fewer radiotherapy sessions.

Intensity Modulated Radiotherapy (IMRT), Image Guided Radiotherapy (IGRT) are two advanced radiotherapy treatment options that are becoming routine in clinical practice across Europe most notably for the treatment of cerebral metastases and skull-based tumours. Similarly Stereotactic Ablative Body Radiotherapy (SABR) is increasingly being used for the treatment of lung cancer.

Adoption of more advanced radiotherapy techniques requires additional support and investment in software and staff training. New treatment protocols also demonstrate that fewer doses, or ‘fractions’, can often be used while achieving the same efficacy.

## **CHEMOTHERAPY**

Chemotherapy and other systemic therapies also play an essential role in the treatment of cancer. Chemotherapy, like radiotherapy, can be used as a curative treatment, as part of a treatment plan incorporating surgery and/or radiotherapy and/or in a palliative capacity.

Chemotherapy can affect people in a variety of different ways and can often carry the risk of short-term and long-term side-effects. Safe delivery of chemotherapy is supported by information technology (IT) systems, including an appropriately specified electronic prescribing and administration system. This is essential to ensure that when undergoing chemotherapy individuals, carers, primary care and out-of-hours services can access information detailing the nature of the chemotherapy treatment regime, any potential side effects and appropriate management information at any time of day or night.

Cancer centres and local hospitals providing chemotherapy already have systems in place to support chemotherapy delivery but further improvements are needed.

## **SYSTEMIC ANTI-CANCER THERAPY (SACT)**

SACT encompasses both biological therapy (therapies which use the body’s immune system to fight cancer or to lessen the side effects that may be caused by some cancer treatments) and cytotoxic chemotherapy (a group of medicines containing chemicals directly toxic to cells preventing their replication or growth, and so active against cancer).

In 2012 we set out revised guidance<sup>63</sup> for the safe delivery of systemic anti-cancer therapy. The SACT working group, convened by Healthcare Improvement Scotland in September 2012, developed a Governance Framework and audit tool to support the implementation of this guidance and to assist NHS Boards in self-assessing SACT services.<sup>64</sup>

It is essential that all NHS Boards submit SACT related data regularly and consistently to support quality improvement of services.

## **ACCESS TO MEDICINES**

We have introduced a range of changes in recent years which are seeing an increase in access to new medicines, including cancer medicines, in Scotland. We want to continue to see the appraisals system for making medicines available on the NHS evolve.

Fair pricing of cancer drugs remains a challenge and we will consider our systems to ensure that Scotland gets best value. We also need to do more in taking a systematic approach to whether new medicines deliver the value that has been shown in clinical trials. We are supporting a project led by NHS Greater Glasgow and Clyde on the clinical effectiveness of cancer medicines in a real life setting.

While the focus is often on new medicines, the increase in repurposing of older off-patent medicines presents opportunities for

improved outcomes. Unlike newly licensed medicines there is currently no comprehensive approach to assessing repurposed off-patent medicines and recommending their use across Scotland. There is a need to ensure that we are well placed to maximise the opportunities of these medicines and therefore work will be undertaken to establish what improvements can be made to our current approach.

## MOLECULAR PATHOLOGY

Molecular Pathology services have been nationally commissioned as a single designated multi-site national specialist service for NHSScotland from 1 April 2013. Tests are provided on four sites within regional centres – Aberdeen, Dundee, Edinburgh and Glasgow with work ongoing to reduce unnecessary duplication and ensure equity of access across Scotland. These molecular genetic and cytogenetic laboratories work collaboratively to provide a range of molecular and cytogenetic tests as determined by the Scottish Genetic Laboratory Consortium.

The Molecular Pathology Consortium (MPC) Steering Group provides a forum for collaborative discussion and decision making on molecular pathology testing in Scotland. Decision making on tests provided nationally are taken by the Consortium on the recommendations of the Molecular Pathology Evaluation Panel (MPEP).

MPEP has responsibility for evaluating molecular pathology tests based on available evidence. Tests are assessed against set criteria and the Panel makes recommendations to the MPC on the clinical validity, analytical validity and clinical utility of tests that should be provided on a national basis in Scotland. Precision medicine is also an area which will have a large beneficial impact in the treatment of cancer and within this genomics has the potential to transform oncology and cancer

care and outcomes. The research chapter has more detail on plans in these areas.

## WAITING TIMES

We are committed to ensuring that all those who require treatment for cancer should receive that treatment as soon as clinically appropriate and that people are provided with a clear treatment summary in a way that is most appropriate for their individual needs.

Cancer waiting time targets were first announced in *Cancer in Scotland: Action for Change* (2001).<sup>65</sup> *Better Cancer Care, An Action Plan* (2008)<sup>66</sup> reviewed and replaced these waiting times with two more challenging targets:

- a 31-day target from decision to treat until first treatment for all new cancer diagnoses (irrespective of the route of referral into the system); and
- a 62-day target from the date of urgent referral with suspicion of cancer to date of first treatment. This 62-day target includes referrals from national cancer screening programmes.

It is acknowledged that the pathway to diagnosis and staging (and therefore to a decision-to-treat date) can involve several medical investigations and decision-making processes. There is evidence that the complexity of the diagnostic, staging and treatment pathways is increasing and that there are considerable differences in pathway complexity across tumour types that makes a ‘one size fits all’ approach to measuring access less meaningful and person-centred.

62-day cancer access standard performance is one indicator of the impact of diagnostic demand on the system.

We have seen improvement in waiting times performance since 2007. In Q1 2007, 1,764 people (84.5% from 2,088 eligible) were treated within the 62-day standard. In Q3 2015 2,757 people (90.0% from 3,064 eligible) were treated within the 62-day standard.

The 31-day standard has been consistently met since its introduction in 2010 with the median wait only 7 days in Q3 2015.<sup>67</sup>

We recognise that these targets are challenging for NHS Boards given the increasing pathway complexity. We have therefore introduced closer scrutiny and performance support measures, and provided an additional £5.25 million to NHS Boards to improve performance in 2015.

To ensure first treatment occurs within the 62-day timescales, an early first appointment to see a consultant is expected. In choosing not to apply targets for first outpatient appointment or cancer pathway diagnostics, the aim was to minimise the burden of data collection and allow NHS Board resources to be used appropriately to meet the treatment time standards. Therefore, for many of the current 62-day tumour specific standards there is an expectation that patients will have an initial consultation within around 2 weeks, and that, where appropriate, diagnostic and staging investigations can be completed within around 2 weeks of that consultation.

We anticipate a challenging position in diagnostic capacity. By 2039, the number of people in Scotland aged 65 or over is expected to increase by 53% to 1.5 million people.<sup>68</sup> Given the incidence of cancer amongst older people, this will have considerable impact on NHSScotland

diagnostics capacity and suspected cancer referrals.

Targets must be person-focused, provide clear clinical benefit and be considered against the risk of unintended consequences.

## CHILDREN AND YOUNG PEOPLE

Our commitment to improving outcomes for children and young people with cancer is absolute.

Cancer is relatively rare in children, accounting for less than 1% of all cancers. In Scotland there are approximately 150 new cases every year. Leukaemia is the most commonly diagnosed cancer in children and this, together with brain tumours and lymphomas, account for more than two-thirds of all cancers diagnosed in children. Cancer presenting during early adult life between 16 – 25 years is rare with approximately 180 cases occurring in Scotland.<sup>69</sup>

The Managed Service Network for Children and Young People with cancer (MSN CYPC), which has been in place since in April 2011 is charged with delivering the Scottish Government's vision for cancer services – to ensure that children and young people in Scotland with a diagnosis of cancer attain the best possible outcomes, have access to appropriate specialist services, as locally as possible that are both safe and sustainable, and that the pathway of care is as equitable as possible regardless of where they live in Scotland. The MSN is continuing to embed the Getting it Right for Every Child (GIRFEC)<sup>70</sup> which should ensure that this holistic approach to improving wellbeing is evident throughout children's cancer services. It aims to improve the wellbeing of children with cancer across all domains: ensuring safety; improving health; maximising achievement; ensuring they are nurtured; being as active as possible; having

their rights and views respected; developing their personal responsibility; ensuring they are included in their community.

The MSN launched its second Cancer Plan; Right diagnosis, right treatment, right team, right place; *The Cancer Plan for Children and Young People in Scotland 2016–2019*<sup>71</sup> which moves to the next phase, ensuring that the child is at the centre and it takes account of relevant legislation and strategies that have emerged since 2012. The Plan sets out how it will achieve its aim of “Right Diagnosis, right treatment, right team, right place”. Priorities identified for people with cancer include:

- early diagnosis and ensuring treatment is started without delay;
- equitable access to the appropriate care and support at time of first diagnosis;
- an identified key worker at every stage of the care pathway;
- provision of information which will also be made available to families and carers;
- knowledge that their treatment has been discussed nationally to ensure that care is given safely in the most appropriate place;
- access to appropriate clinical trials and recruitment to those trials;
- care will be age appropriate;
- access to holistic care will be equitable;
- there will be an ongoing assessment of needs during and after treatment; and
- ongoing support after cancer to ensure the best quality of life after treatment.

## Actions – Improving Treatment

- Apply the National Clinical Strategy to cancer services, keeping services as local as possible and exploring those surgical interventions that would be better delivered by planning services across a larger population.
- Invest a further £2 million of capital to support our nationwide programme which will see two further robots for prostate cancer surgery in place, one in Glasgow and one in Edinburgh.
- Invest further £39 million in radiotherapy equipment over 5 years. This includes £8 million investment in 2016-17.
- We will also invest in two radiotherapy physics trainee posts over 2015-16 and 2016-17 to help build capacity in radiotherapy services.
- Introduce a new gene expression profiling test for all women with breast cancer who would clinically benefit from it, Oncotype DX. The Molecular Pathology Evaluation Panel advised on this, the test aims to improve the targeting of chemotherapy in breast cancer by more accurately identifying individuals who will gain the most benefit. It is estimated that this may help around 25% of relevant women avoid unnecessary chemotherapy treatment.<sup>72</sup>
- Examine whether additional targets for treatment or diagnosis would improve outcomes for people with cancer
- Invest an additional funding of up to £2.5m to enable the MSN to lead and deliver the improvements set out in their second Cancer Plan.
- We will consider the recommendations from the independent review on new medicines reporting in Summer 2016 and what further changes need to be made.
- We will invest £7.5 million over the next 5 years to support improvements in surgical treatments, including urological cancer surgery.
- Invest £1 million in a project led by NHS Greater Glasgow and Clyde on clinical effectiveness of cancer medicines in a real life setting.
- We will assess what improvements can be made to how we maximise opportunities for access to off-patent drugs.

# 7. WORKFORCE



## 7. WORKFORCE

### Our Ambitions

**To have a diverse, sustainable, workforce caring for people with cancer.**

**To support equity of access to specialist care regardless of geography.**

**To see all people with cancer, who need it, have access to a specialist nurse during and after their treatment.**

People with cancer require sustainable care across a spectrum comprising primary and community care, diagnostic services, treatment and care after their treatment, palliative and end-of-life care.

That means a wide range of skilled staff provide advice, support and targeted care to individuals with cancer. Many of these staff may not specialise in cancer but nevertheless have a broad range of knowledge and skills equally as relevant for each person. Workforce planning is therefore key to ensuring we have in place all of the relevant skills and expertise required in general practice, in the community and in secondary and tertiary care provided in hospitals across the country.

Acknowledging the complexities of a challenging clinical area, we know that for some healthcare professions and specialities it can be difficult to recruit staff. For all services, we work closely with NHS Boards to support their efforts to recruit and retain highly skilled staff.

But, as noted throughout this plan, we know demand for services is rising, fuelled by our ageing population with the consequential

increase in the number of cancer diagnoses per year, and the broader spectrum of services required by people living with cancer. While we know that through their unstinting efforts our existing workforce has so far coped with these pressures, we need to find more sustainable approaches to delivering person centred services across the spectrum from primary/community care to highly specialised care over the longer term.

Evidence shows that we are moving in the right direction.

The total NHS workforce in Scotland has grown to an all-time high of 161,000 (138,000 WTE). Looking at just one of the specialties closely associated with cancer care, we have seen numbers of consultant clinical radiologists increase by 97.3 WTE, or 43.5% under this Government and by 12.3% in the last 2 years. In terms of future medical and nursing supply, the £27 million announced in February 2016<sup>73</sup> to train additional nurses and doctors is a contribution towards ensuring Scotland's NHS has a more sustainable workforce, some of whom will be involved in providing the cancer services of the future.

NHS Education for Scotland (NES) has already taken steps to increase the number of Radiology training posts by 16 places over the past 3 years and will keep this trainee establishment under review. Clinical oncology training posts have also been increased by six over the past 2 years in recognition of the need for further growth in the consultant establishment. For therapy radiographers (who support planning and delivery of radiotherapy) 32 additional training places were put in place. The second tranche of training for the previous intake of radiographers has now started and this 3-year programme will be completed by end 2016-17.

## PLANNING FOR DEMAND

Rising demand for cancer services is not unique to Scotland, and several European countries are experiencing similar issues. In October 2015 the Royal College of Radiologists reported that Scotland has around seven radiologists (consultant and trainees) per 100,000 population. This is comparable to the rest of the UK but is lower than other European countries including Germany (11 per 100,000), Finland (13 per 100,000) and Norway (12 per 100,000).

Many NHS professions provide cancer services, and having sufficient staff is vital to providing any high quality service. But numbers alone will not meet the constantly shifting challenges. That means we must maximise the contribution from the whole healthcare workforce, and deliver high quality services as flexibly as we can to those who need them. It means considering the wider characteristics of the workforce required to provide high quality services – drawing on the full range of professional skills offered, for example, by Specialist Nurses, Advanced Nurse Practitioners, by allied health professionals such as Radiographers, Speech and Language Therapists and/or by those who

work within the Healthcare Sciences. Some individuals will continue to require the support of specialised staff who can provide the highest quality high technology care available. Others may need more generalist care. The complexity of this clinical environment means there is often no single solution about how to provide the best balance of treatment and care. Skilled planning involving professional judgement is required in finding the right workforce to provide the best possible outcomes, involving:

- Combining generalist as well as specialist skills.
- Working effectively in teams.
- Valuing the contribution of all disciplines to addressing individual needs.
- Excellent generic skills, such as listening, communication, leadership and improvement skills.
- Engaging in life-long learning, recognising the pace of change in health and social care.
- Remaining flexible, able to adapt to changing technology and individual need.

Risk can arise in over-emphasising workforce issues at the expense of service planning and delivery, and solutions which may have worked previously may no longer apply. It is therefore worth restating that planning for the right workforce cannot and must not be carried out in isolation. Many factors combine to influence this, including demand for services, new technology, new developments in diagnosis and treatment or location. This has particular relevance for cancer services planning and delivery across the country.

Providing Scotland's people with high quality services requires sufficient numbers of the right staff in the right location with appropriate skills. That applies universally to the services NHSScotland delivers. But harnessing the knowledge, skills and attributes of the workforce, and deploying them in

the right way, are particularly important for cancer services which involve so many different aspects of diagnosis, treatment and care, and such a diversity of professional challenges.

Just as our National Clinical Strategy sets the direction for NHS services, including cancer services, our framework for *Everyone Matters: 2020 Workforce Vision*,<sup>74</sup> provides a clear workforce vision and plan, thought through and co-produced with our staff. We continue to support our workforce alongside staff side partners through the priority areas identified in that plan:

- Healthy organisational culture
- Sustainable workforce
- Capable workforce
- Workforce to deliver integrated service
- Effective leadership management.

## **Actions – Workforce**

- Workforce planning for cancer, including for training and education, will move to be undertaken on a national basis over time. This will be taken forward in our well-established partnership approach to create the sustainable workforce we need for the future. This will ensure that workforce planning for cancer spans the entire cancer care pathway and will complement the workforce vision and plan in *Everyone Matters*.
- We will put the necessary levels of training in place to ensure that by 2021 people with cancer who need it have access to a specialist nurse during and after their treatment and care.
- We must ensure that our investment in radiotherapy equipment is being fully utilised and delivering to its full potential, so we are making at least £11 million available over the next 5 years to support additional radiotherapy training and staff for these specialist services. A sub-group (of NCCSG) are developing a plan, including appropriate training and support, to ensure that advanced radiotherapy techniques become the norm.

# 8. LIVING WITH, AND BEYOND, CANCER

A close-up photograph of a woman with blonde hair, wearing a blue top, smiling warmly at the camera. She is holding a young child, whose face is partially visible on the left side of the frame. The background is softly blurred.

## 8. LIVING WITH, AND BEYOND, CANCER

### Our Ambitions

**To help people living with, and after, cancer treatment have access to information, advice and support tailored to their individual needs.**

**To ensure that, by 2021, everyone in Scotland who needs palliative care will have access to it.**

As more people are surviving longer as a result of effective screening programmes, earlier diagnosis and better access to advanced treatment techniques and therapies as set out throughout this plan, it is recognised that some individuals will be cured while others will be living with their disease for years, making cancer, or at least some types, a chronic condition.

Our estimates suggest that for every 1,000 people in Scotland, there may be up to 30 to 35 cancer survivors, eight or more of whom may be experiencing significant consequences of their cancer and its treatment.

We already know that a cancer diagnosis has a considerable psychological impact. The disease itself is often associated with fatigue and other physical effects, but also social, financial and relationship issues which may impact on recovery. There are increasing numbers of people living with multiple co-morbidities, of which cancer may be one. Unlike the management of other chronic diseases, cancer treatments – surgery, radiotherapy and systemic therapies – can have unique and sometimes serious short-medium and long-term consequences.

In an effort to improve our survival deficit,

we have been rightly focused on early detection, access to high quality treatment and supporting individuals through their treatment. But as we learn from the experiences of those living with and beyond cancer it is no longer acceptable to focus on these areas alone. We now recognise that more needs to be done to improve the quality of life for people who have been diagnosed with and treated for cancer.

Our focus has widened beyond acute treatment and extends to ensure a good recovery from cancer, acknowledging that improvements in survival must be accompanied by a recognition of the ongoing health and wellbeing needs of survivors and, as appropriate, the consequences of their treatment.

As more people are living longer following diagnosis and treatment of cancer, more are experiencing the consequences of treatment or a second primary cancer. It is essential that such consequences are prevented where possible. We will support efforts to identify and appropriately manage those at risk.

No matter how well existing processes are working in support of people with cancer, there is always more that can be done to

improve their care. This means listening to the feedback from individuals and carers/families.

It may require system and organisational change to promote and deliver the roles and skills necessary for true person centred care. Such system change is articulated in models such as the House of Care,<sup>75</sup> which provides a useful representation of the components, all of which are required, to place collaborative, relational decision making and planning at the heart of person-centred care.



In addition, the National Links Worker Programme is working to understand how the primary care team can support people to live well in their community, embedding a dedicated resource – a Link Worker – to make connections between people and sources of support, often drawing upon third sector expertise. When individuals feel supported in their lives, they are more likely to respond to information on ways to improve their health and to live well. If these people are successfully supported sooner rather than later then there is a potential that their risk of developing long term conditions can be reduced.

We also need to ensure that people have the knowledge, understanding, confidence and skills to live well on their own terms and with the health conditions they have. Our

health literacy action plan, *Making it Easy*,<sup>76</sup> sets all of us a challenge as to how we make healthcare simpler and more engaging so that it is responsive, particularly to those with the greatest health literacy needs and those with the least support.

## TRANSFORMING CARE AFTER TREATMENT

As more and more people are living for longer after a diagnosis of cancer, evidence suggests that their increasingly complex needs are not being met by traditional medically-led follow-up care. It is important that people do not feel a sense of abandonment at the end of treatment.

Work is already well underway, in partnership with Macmillan Cancer Support, through the Transforming Care after Treatment (TCAT) Programme.<sup>77</sup>

We know that people can feel vulnerable and isolated after a period of hospital treatment. We must ensure, through NHS Boards and relevant services, that secondary and tertiary hospital cancer services communicate and work with primary and community health services, social care and our third sector colleagues to ensure the transition from acute care is not only supportive but meets the needs of the individual.

Every individual should know about their treatment and have the information needed to help put them in control of their own care. To do this a co-operative approach is needed across health and social care.

Promoting the adoption of follow-up that is person-centred and risk-stratified, supported by a holistic needs assessment and individual care plan for everyone following their treatment will lead to improvements in the quality of care delivered.

The Scottish Primary Care Cancer Group, with funding assistance from Macmillan Cancer Support, will examine how best to ensure that everyone is given a Treatment Summary so that they are informed about their own care but also so that this can be used in discussion with clinicians and other professionals throughout the course of their ongoing care and support.

The Improving the Cancer Journey<sup>78</sup> experience in Glasgow is an example of how an integrated approach to implementing the components of the Recovery Package<sup>79</sup> across health and social care can lead to an improvement in quality of life, person-led post-treatment rehabilitation and ability to self-manage.

## PALLIATIVE CARE

Palliative care and care at the end of life needs to be responsive to the changing preferences and priorities of people with advanced illness and those of their carers. All health and care workers require an appropriate level of knowledge and skill in palliative and end of life care. Holistic high quality care must be delivered for everyone in accordance with the appropriate legal, professional, clinical and care standards.

It is not just about care in the last months, days and hours of a person's life about enabling someone to live with a life-threatening condition and maintaining as far as possible the quality of life for people living with cancer and their families. As well as controlling pain and other distressing symptoms, it is about helping individuals and their families cope with the emotional upset and practical problems of their situation and supporting them and their friends in their grief and bereavement. The needs here are the same as those of anyone living with a long-term condition. Many people with cancer

can benefit from a palliative care approach delivered across health, social care and community settings.

A person's diagnosis or condition significantly influences the care and support they can access, where they are cared for and funding for their support and accommodation. There can also be inequalities in access, treatment and support arising through socioeconomic and educational disadvantage, and associated with particular individual characteristics such as age, ethnic group, religion or belief and sexual orientation. Particular groups in society may also be disadvantaged, such as people who are in prison or who are part of a travelling community. There are also issues when considering the transition to adult services for young people with palliative care, respite and support needs.

In December 2015 we published our *Strategic Framework for Action on Palliative and End of Life Care (2015)*<sup>80</sup> which sets out how key stakeholders can apply the 'Three Step Improvement Framework for Scotland Public Services'<sup>81</sup> to support improvement in services.

Through the implementation of the Framework will seek to ensure that people:

- receive health and social care that supports their wellbeing, irrespective of their diagnosis, age, socio-economic background, care setting or proximity to death;
- have opportunities to discuss and plan for future decline in health, preferably before a crisis occurs, and are supported to retain as much independence as possible, for as long as possible; and
- know how to help and support each other at times of increased health need and in bereavement, recognising the importance of families and communities working alongside formal services.

## **Actions – Living With, and Beyond, Cancer**

- We will work to ensure that every person with cancer is given a Treatment Summary.
- To ensure that there is capacity in our health and social care services to address any unmet needs of people living with and beyond cancer, the three Regional Cancer Networks and the TCAT Programme Board will develop and implement risk stratified person centred follow-up protocols that will reduce unnecessary and ineffective reviews.
- In an effort to improve health and reduce the risk of secondary disease or a second primary cancer, we will ensure that physical activity advice and services (described in the earlier chapter on cancer prevention) are available for people recovering from cancer.
- We will use the National Cancer Patient Experience Survey and the Patient Experience Quality Performance Indicators to help inform us how unmet need is being addressed.
- We will consider the outcomes from the TCAT programme as it progresses and through its evaluation strategy.
- Invest £9 million over 5 years to support access to health and social care services during and after treatment, via for example, Link Workers to provide support in the most deprived communities and initiatives such as Macmillan's *Improving the Cancer Journey*.
- We will invest £3.5 million over 4 years to drive improvements across the palliative care sector and to support targeted action on training and education that support the aims of the Framework.
- With some social security powers being devolved to Scotland we will be founding our action on welfare based on treating people with dignity and respect. This includes giving a rounded assessment of people's needs, streamlining the administrative process, and seeking to fast track for those that qualify and are living with a terminal illness such as cancer.

# 9. QUALITY IMPROVEMENT



# 9. QUALITY IMPROVEMENT

## Our Ambitions

**To become one of the highest performing cancer healthcare systems internationally.**

**To improve data sharing, including in real time, to drive improvements in care, quality health delivery, improvement programmes, performance management and research.**

Accurate and systematic recording and collation of data is fundamental to improving outcomes for people with cancer, and tackling the problem of Scotland's higher cancer mortality relative to other similar countries.

### DATA AND INFORMATICS

Access to high quality, accurate data is an essential part of good person-centred care. The highest performing healthcare systems internationally are supported by data sharing, often in real time, to enable person-centred care, quality healthcare delivery, improvement programmes, performance management and research. Accurate and systematic recording and collation of data is fundamental to improving outcomes and tackling the problem of Scotland's higher cancer mortality relative to other similar countries.

NHSScotland is awash with cancer data. The problem is that it currently exists in separate and unlinked locations. In England, similar problems have been overcome through the development of the National Cancer Registration System (NCRS) and the National Cancer Information Network (NCIN) within Public Health England (PHE). These bring together all available cancer information by a process of 'scraping' the data from various

locations and processing it to achieve a coherent record of the individual's journey, accessible by clinicians in near real time, and available for secondary uses as such as service planning, audit and research. PHE have very recently merged these central cancer registration and analysis functions to create the National Cancer Registration and Analysis Service (NCRAs).

A problem – but above all an opportunity – facing the whole of modern health care is the rapidly increasing amount of data potentially available to inform and improve care. Currently, Scottish cancer services devote significant energy and resource to managing and using cancer data. In areas where electronic solutions and support are lacking, Boards and regions have had to develop a range of 'work arounds' to access and use these data, often involving significant human resource around data entry/re-entry.

The complex and multifaceted nature of cancer care, with its emerging new diagnostic (e.g. genomics) and treatment, such as immuno-oncology, modalities, is leading to the generation of massive data sets which will need to be organised and harnessed to optimise outcomes.

To achieve this will require the involvement and collaboration of many individuals and organisations and will demand a sustained effort over a period of years. The ultimate prize will be the establishment of the 'Scottish Cancer Intelligence Framework' (SCIF), where relevant cancer data can be effectively, efficiently and securely captured, moved, filtered, stored, quality assured, analysed and visualised for a range of purposes outlined in the box below.

The Scottish Cancer Information Framework (SCIF) aims to ensure systems are in place to:

- Enable all eligible clinicians involved in the care of people living with cancer to have direct, near real time access to cancer data.
- Enable all eligible people living with cancer to access their own data to support and facilitate self-management.
- Improve cancer audit processes and generate an ethos of continuous quality improvement which addresses inappropriate variations in treatment and outcomes.
- Support better performance management and service planning of cancer services.
- Benchmark cancer services and outcomes in Scotland with the rest of the UK and more widely.
- Enhance research and innovation opportunities in Scotland.

Many of the foundations and clinical support needed to deliver this framework are already in place. For other elements there is much still to be done. To focus and coordinate effort, the Innovative Healthcare Delivery Programme (IHDP)<sup>82</sup> was established in 2015.

This programme, which is embedded in the Farr Institute, aims to harness the power of informatics to deliver value directly to individuals, healthcare professionals and the wider NHS through collaborations with

academia, industry and the third sector. The IHDP team has recently undertaken a series of visits to all five Scottish cancer centres, to map data sources/systems and gather intelligence more widely. These visits have further highlighted the technical and organisational barriers that exist developing SCIF, as well as identifying information gaps.

Key amongst these is the need to capture data from Multidisciplinary Team (MDT) discussions across Scotland and all tumour types. MDTs are the hub of the clinical decision making process and there is an urgent need to provide them with more support. More generally, the IHDP is providing leadership around the task of re-engineering and extending national data flows to create a dynamic national cancer registration service, focused on improving outcomes.

## **NATIONAL CANCER QUALITY PERFORMANCE INDICATORS PROGRAMME**

The NHS has a duty to deliver the best standard of care based on the latest available evidence. The role of SIGN in developing evidence-based guidelines therefore remains essential. There is also a recognised need for national cancer quality performance indicators to support a culture of continuous quality improvement in NHSScotland.

Addressing variation in the quality of cancer services is pivotal to delivering the improvements envisaged in this plan. This is best achieved if there is consensus and clear indicators for what good cancer care looks like.

Through the auspices of the National Cancer Quality Steering Group (NCQSG), National Cancer Quality Performance Indicators (QPIs) were developed to drive continuous quality improvement in cancer care across

NHSScotland. Small sets of cancer specific outcome focussed, evidence based indicators are in place for 18 different tumour types. These are underpinned by patient experience QPIs that are applicable to all, irrespective of tumour type.

These QPIs ensure that activity is focused on those areas that are most important in terms of improving survival and individual care experience whilst reducing variation and supporting the most effective and efficient delivery of care for people with cancer.

This programme is supported by Healthcare Improvement Scotland (HIS). *The National Cancer Quality Programme CEL 06 (2012)*<sup>83</sup> requires NHS Boards to report against QPIs as part of a mandatory, publicly reported, national programme. A rolling programme of reporting is now in place with three national tumour specific reports published annually.

National reports, published by HIS include comparative reporting of performance against QPIs at Board level across NHSScotland, trend analysis and survival. This approach helps overcome any issues relating to reporting of small volumes in any one year.

In addition to the three yearly national tumour specific reports, NHS Boards are required to collect data and analyse these on a yearly basis so that Regional Cancer Networks can then produce annual action plans to address any areas of variance or concern and report them via the relevant Regional Cancer Advisory Group. These are published on the websites of Regional Cancer Networks.<sup>84, 85, 86</sup>

HIS undertake independent assurance of the performance and progress against QPI data at the three yearly point. This ensures that both Boards and Regions are working cohesively towards continuous improvements

in the quality of services. This process also considers other evidence such as action plans, the governance structure of RCAGs and clinical narrative to ensure that services have improved over a period of time or are working to improve. It also allows clinical networks a voice in the process and an opportunity to consider their own progress and to challenge progress at a national level.

A programme to review and update the QPIs in line with evolving evidence is in place as well as a robust mechanism by which additional QPIs will be developed over the coming years.

## PERSONAL EXPERIENCES

In Scotland, national surveys of patient experience of hospital and GP services have been in place since 2010 and, as noted above, the Cancer Quality Performance Indicators Programme has developed Cancer Patient Experience QPIs. Indicators were developed based on existing high quality patient experience evidence together with a public engagement process supported by the Scottish Health Council. There is measurement of three indicators – communication, information-giving and shared decision making. A survey of patients receiving radiotherapy across the five centres in Scotland was also carried out and reported in 2014.<sup>87</sup>

In October 2014, the Cabinet Secretary for Health and Wellbeing announced a commitment that the Scottish Cancer Taskforce (SCT) would carry out a national experience survey amongst people with cancer. This is now being carried out and the findings are expected to be published in Summer 2016.

The Quality Strategy acknowledges that high quality experience of care is valued by

people with cancer and should be prioritised alongside achieving excellence in clinical outcomes and waiting time targets. A poor experience of the care delivered can impact on a person's health and can adversely impact upon illness recovery. We are committed to promoting a positive experience of care for all people with cancer and ensure that they, their families and carers are treated with dignity, kindness, respect and compassion.

We know that people value most highly the dimensions of patient-professional interactions, communications, and being treated as an individual. We also acknowledge the link between individual experience, safety and the need for dignity and experience to be at the heart of care delivery.

We fully anticipate that health and social care services across the country will use the forthcoming results from the National Cancer Patient Experience Survey to benchmark performance on the issues that matter to people with cancer, and to use the information to improve the way that care will be delivered.

## Actions – Quality Improvement

- We will provide up to £2 million additional funding over 2 years to support IHDP to deliver its aims.
- The NCQSG will improve data collection on secondary and recurrent cancers in order to better understand any issues these present for the quality and delivery of care and to examine ways in which we can provide improved support to individuals so affected.
- We will support and fund a National Cancer Patient Experience Survey, keeping under review how best to measure what matters to people with cancer and ensuring appropriate action is taken on results.

# 10. RESEARCH

A photograph of a scientist in a white lab coat and blue gloves conducting research. The scientist is holding a wooden clothespin with two test tubes attached to it over a small electronic device, possibly a spectrophotometer. In the background, there are shelves filled with various glassware and laboratory equipment under bright blue lights.

# 10. RESEARCH

## Our Ambitions

**To embed research in the ethos of our healthcare services.**

**To give individuals access to, and opportunity to participate in, clinical trials appropriate to their circumstances.**

**To support a clear programme of research targeted at improving outcomes and/or experiences of cancer.**

Research is essential to enable developments to improve cancer prevention, diagnosis and treatment..

Through its own response mode grant schemes, and co-funding arrangements with the National Institute of Health Research, cancer research charities, and Research Councils, the Scottish Government Chief Scientist Office (CSO) provides funding opportunities for the academic community in Scotland for research into the prevention, diagnosis and treatment of cancer.

Through investments in the NHS Research Scotland infrastructure CSO supports clinical research networks, data safe havens and accredited tissue biorepositories to facilitate recruitment to cancer studies and the use of tissue and health data in cancer research. In addition, recent large-scale strategic investments in genomics and precision medicine (see below) provide new opportunities for cutting-edge research to understand better the genetic and molecular profile of cancers and the support the development of new more effective diagnostic approaches and treatment strategies targeted to individuals.

We know that a research-active health service delivers better outcomes and we are working to embed research in the ethos of our healthcare system. Individuals benefit through access to novel therapies and the ongoing implementation of evidence-based best practice. In the longer term, research provides understanding of the causes of cancer, leading to benefits at the population health level.

Recent advances in the understanding of cancer biology have allowed many cancers to be stratified into sub-types based on their genetic profile, meaning that individuals are beginning to be offered more personalised treatments tailored to their particular tumour type. The availability of well-characterised individual cohorts, tissue or specimens, and/or data is essential to support the transition to more personalised medicine and to support a wide range of research.

The creation of a network of NHS Research Scotland (NRS) biorepositories<sup>88</sup> for the supply of tissue to meet non-commercial and industry research needs has been supported by CSO infrastructure investment to Scottish Health Boards in Grampian, Greater Glasgow and Clyde, Lothian, and Tayside. These operate as separate biorepositories managing their

local archival and project stored tissue but working as a network sharing good practice and in the provisioning of samples from across Scotland.

Through CSO infrastructure investments safe havens have now been established in the four nodes of NHS Research Scotland to facilitate health research across Scotland using routinely collected health and other relevant data. Together, these safe havens are forming a federated network working to agreed principles and standards to collaborate on research studies and to share best practice. Other cancer specific research projects funded by CSO currently underway include:

- £250,000 for a project comparing Laparoscopic and Robot-Assisted Radical Prostatectomy performed by experience and volume-matched surgeons in Edinburgh and London across a number of parameters, including individual-reported outcomes.
- £169,504 over 3 years to investigate JAK2 targets in haematological malignancy.
- £153,774 over 3 years to develop a measurement-guided medicine intervention to optimise cancer pain control.

Partnerships with third sector colleagues is vital to supporting research and there are a number of jointly funded initiatives under way, for example:

- Along with Cancer Research UK Experimental Cancer Medicine Centres in Glasgow and Edinburgh/Dundee. These form part of a UK-wide network of 18 centres established to drive the discovery, development and testing of new cancer treatments, including for breast cancer. The Scottish Government provides annual funding of £350,000 to support this initiative.
- £450,000 to support Scottish-led breast cancer research in partnership with Breast Cancer Now.
- In pancreatic cancer CSO is co-funding of £150,000 for Pancreatic Cancer UK's Research Innovation Fund. With additional

funding from Pancreatic Cancer Scotland there is currently approximately £400,000 available for pancreatic cancer research in Scotland.

## PRECISION MEDICINE AND GENOMICS

Precision medicine is a field which has the potential to transform health care in the years ahead. It is expected to bring benefits for individuals and for the health service alike by reducing the risk of wasteful and ineffective prescriptions, providing better and more effective personalised treatment to individuals, tailored to their genetic make-up and the particular characteristics of their disease.

In February 2016 the First Minister committed £4 million to support research into precision medicine to help build the infrastructure needed to support development and commercialisation.

By knowing the whole genome sequence, it may be possible to offer a diagnosis where there hasn't been one before, understand better the cause of disease and work out how best it might be managed.

On 1 March 2016, the establishment of the Scottish Genomes Partnership was announced. This will see further investment of £4 million from the Scottish Government and £2 million from the Medical Research Council. This Partnership, which is a collaboration of Scottish Universities and the NHSScotland genetics services, working with Genomics England on the diagnosis of rare diseases using whole genome sequencing to support the use of whole genome sequencing in programmes of research on a number of rare genetic diseases including some cancer types.

This builds on £15 million investment in whole genome sequencing technology by the Universities of Edinburgh and Glasgow.

## CLINICAL TRIALS

The recruitment of people into clinical trials is essential if the potential benefits of new therapeutics are to be realised. Through the CSO we provide funding to support the Scottish Cancer Research Network (SCRN) whose remit is to increase, support and sustain clinical trial activity in cancer.

Over the period 2012-15, the network supported the recruitment of, on average, more than 7,600 Scottish people into cancer clinical trials. The important role of the network was recognised by the appointment in 2014 of an NRS Cancer Research Champion. This CSO-funded post provides leadership and support for the future development of the SCRN's role in promoting and delivering cancer clinical trials in Scotland.

A distinct feature of the Scottish research landscape is the close working between the NHS Research Scotland Ethics Service and the Health Board R&D offices, which has removed some of the artificial barriers between these two functions and streamlined the process of obtaining the necessary approvals for study commencement. As part of our *Delivering Innovation through Research – Scottish Government Health and Social Care Research Strategy*<sup>89</sup> the CSO is working to ensure that

Scotland continues to lead the agenda on streamlining the research approvals process and reducing bureaucracy, recognising that there is scope for further improvement.

New EU Clinical Trials Regulation, likely to come into force over the next few years, will streamline the authorisation process and harmonise requirements for clinical trials in Europe. One of its key features means that applicants will only have to submit a single application for a clinical trial, regardless of the number of participating member states, and, in Scotland, this will mean that a single decision on a clinical trial will replace the current separate approvals given by the Medicines and Healthcare products Regulatory Agency and the Research Ethics Committee.

Through the new Regulation there will be clear opportunities for Scotland to capitalise on this new efficient approach and the CSO will ensure Scotland's readiness when the new Regulation is implemented.

## Actions - Research

- We will build on our research expertise and investments in precision medicine by funding two research exemplars in ovarian and pancreatic cancer, progressing genetic understanding of these diseases and supporting the adoption of genome-based treatment in to the NHS.
- We will work with the UK regulatory authority to introduce greater flexibility in the clinical trial activities that can be undertaken away from the core site, allowing cancer people with cancer across Scotland greater access to studies being led from the central belt.
- We will continue to invest in cancer research infrastructure, and will work with Cancer Research UK to support the continuation of the Experimental Cancer Medicine Centres for a further 5 years.

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