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Welsh Government

Cancer Delivery Plan for Wales 2016-2020

The highest standard of care for everyone with cancer

Produced by the Wales Cancer Network
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Foreword

In this refreshed cancer delivery plan, the Welsh Government's commitment to delivering the best possible care and support to everyone affected by cancer is reaffirmed. We have an enormous challenge ahead of us as our growing and ageing population will eventually see 1 in 2¹ of us developing cancer. This demand will be set against the finite resources likely to be available for health and care services in Wales, which makes it challenging to simultaneously improve quality and performance and ultimately the health of our population.

However, our vision remains the same, for services and outcomes for our patients to match the best in Europe. We must aim high and continue to work towards this by making the most of our collective assets in Wales. Not least the skill, dedication and hard work of our clinical staff, service managers and third sector organisations. We should also look to create a more equal relationship between patients and healthcare professionals, enabling people to co-produce their treatment based on what matters to them, their values, goals and circumstances, as well as supporting people to take responsibility for minimising their risk factors for cancer.

Wales is a relatively small country and this allows us to make the most of a collaborative and planned approach. We will continue to bring our providers, stakeholders and commissioners together routinely to deliver this common vision. We will build on our commitment to quality, equity and evidence-based services to make the most of the resources at our disposal. We can draw strength from the consistency of our approach by continuing the delivery plan through to 2020. As well as taking advantage of our ground breaking Wellbeing of Future Generations (Wales) Act, our current and future public health interventions and our world class research base.

At the heart of service quality improvement is tackling variation. Incidence of cancer varies by 23% between the most and least deprived areas in Wales². As a small country with a small number of providers we can do substantially better to tackle differences in services and reduce inequalities. Targeted prevention including diet, tobacco and lifestyle advice, uptake of population screening programmes and equitable access to care, will help to drive down socio-economic and geographical variation in outcomes.

Much progress has been made in recent years. Our one and five year survival rates continue to improve year-on-year and premature mortality (people dying before the age of 75 years) from cancer has fallen by around 14% over the past ten years. Our 2013 cancer patient experience survey also showed that 96% of respondents rated their care positively.³ The cancer plan has created a common vision for the service

¹ Ahmad, A, S. Ormiston-Smith, N. and Sasieni, P, D (2015) Trends in the lifetime risk of developing cancer in Great Britain: comparison of risk for those born from 1930 to 1960. *British Journal of Cancer*. 112, p943–947

<http://www.nature.com/bjc/journal/v112/n5/full/bjc2014606a.html>

² Welsh Cancer Intelligence & Surveillance Unit (2015) *Cancer in Wales: 2001-2013*.

<http://www.wcisuwales.nhs.uk/sitesplus/documents/1111/WCISU%20Official%20Stats%20Report%20Final%20English.pdf>

³ Quality Health (2013) *Welsh Cancer Patient Experience Survey*.

among stakeholders which has been widely welcomed and supported. The implementation structure, including the Cancer Implementation Group and Wales Cancer Network, has matured and will continue to bridge the gap between ambition and delivery.

We have also seen progress in the delivery of more person-centred care, a greater focus on the role of primary care, the creation of acute oncology services and considerable focus on lung cancer – which causes the largest number of cancer deaths in Wales and has not yet seen the improvements in outcome made in other cancer sites⁴. Cancer services also lead the way in the use of quality improvement processes such as national audit and peer review to support compliance with standards. However, there is always much more to be done to embed the delivery plan in services and achieve consistency, more timely care, improved survival and good patient experience. This will be a long-term and incremental journey; one which we must take together.

Dr Tracey Cooper, Chair of the Implementation Group

Introduction

Cancer services in Wales

There are clear reasons why cancer should remain a top priority for the Welsh Government. In 2009 there were around 16,000 new cases of cancer a year in Wales, this has risen by an average of 1.5% a year and in 2014 there were more than 19,000 new cases. Demand is set to rise by at least 2% a year for the next 15 years.⁵ Cancer also accounts for nearly 7%⁶ of all NHS expenditure in Wales and in 2014-15 this amounted to £409 million – the fourth biggest spending area for NHS Wales.

It is an enormous challenge for the health service to absorb anticipated future levels of demand. In terms of productivity the service has responded well. The annual increases in demand have, by and large, not led to reductions in timeliness of care. However, advice from our expert clinicians, patients and the third sector is that no patient should wait more than 62 days from the point of when cancer is first suspected to the start of treatment, and so we must do better. We can do this by reforming clinical pathways, rather than just pushing stretched services even harder. This will include learning from international practice and improving the way we manage patients through complex diagnostic and treatment pathways.

<https://www.quality-health.co.uk/resources/surveys/welsh-cancer-experience-survey/2013-welsh-cancer-experience-survey>

⁴ Welsh Cancer Intelligence & Surveillance Unit (2015) Lung Cancer in Wales.

<http://www.wcisu.wales.nhs.uk/sitesplus/documents/1111/141214%20LUNG%20CANCER%20IN%20WALES%20FINAL.pdf>

⁵ Welsh Cancer Intelligence & Surveillance Unit (2015) Cancer in Wales: 2001-2013.

<http://www.wcisu.wales.nhs.uk/sitesplus/documents/1111/WCISU%20Official%20Stats%20Report%20Final%20English.pdf>

⁶ Stats Wales (2016) NHS expenditure percent of total by budget category and year

<https://statswales.gov.wales/Catalogue/Health-and-Social-Care/Health-Finance/NHS-Programme-Budget/nhsexpenditurepercentoftotal-by-budgetcategory-year>

This service improvement must be clinically led. Organisational and cancer tumour site leads have a vital role to play in leading service improvement. This clinical leadership must focus on the whole system so as to better integrate clinical teams, break down barriers between primary and secondary care; and between diagnostic and treatment teams. Lessons learned from the south west Wales ARCH [regional collaboration for health] and south east Wales TCS [Transforming Cancer Services] change programmes must be extended to cancer services more broadly. To be able to meet future demand, our systems of care must continuously improve through education, research and developing a workforce able to meet the needs of people affected by cancer. Services should be centred firmly on equitable and timely access to evidence-based treatments and be planned, commissioned and delivered where necessary across organisational boundaries.

We must lead a relentless drive towards earlier diagnosis. We are aware that Wales performs less well in this compared to other developed countries worldwide. Diagnosing cancer early allows for a combination of less aggressive and less expensive treatment, improved patient experience and quality of life, and crucially better survival. This will require a programme of improvement focusing on awareness and behaviours of people who might be affected by cancer and among primary care teams; improved screening uptake and the interface between primary and secondary care; improved access and efficiency of diagnostic and treatment services. This must be one of the primary goals for NHS Wales in the coming years.

Improving patient pathways and reducing variation in patient outcomes require us to focus on those interventions that deliver high 'value' healthcare. Increasingly services will be personalised to the biological and genetic signatures of a person's disease. In some cases this will reduce the use of low value treatment and its complications. But this will also require improvements in access to the most up-to-date testing services, such as genomic analysis, and treatments such as image guided, intensity modulated and stereotactic radiotherapy treatments. In some cases this will require reconfiguring diagnostic and treatment services to ensure access to the highest quality and safe care; though services should be delivered as close to the patient as possible. Reducing inequity of access must also include greater consistency and streamlining of the Individual Patient Funding Request process.

We must see the patient as an equal in their care plan, working in true partnership to help them recognise and achieve their goals and supporting them during and beyond treatment. Services must ensure people affected by cancer are at the heart of service design. Particular attention should be given to the points where a patient's care transfers to another organisation or service and consistent application of supporting interventions such as the allocation of a key worker. Increasingly digital technology will support patients and enable them to play a part in their own care; providing access to their own health records, care plans and needs assessments, as well as enabling them to be shared throughout the healthcare system.

The good news is the number of people surviving cancer is increasing. By 2020 there will be 150,000 people living after a prior diagnosis of cancer (5% of the

population); the number having doubled during the previous 15 years⁷. For many people cancer is now a chronic condition which requires a new approach to longer term care, focusing on maintaining a high quality of life through and beyond treatment. Yet we must not forget the need to make this a reality for all cancers, some with particularly poor survival outcomes will need additional focus for the next few years. Cancer services in Wales have a great opportunity to improve patient outcomes by working more closely together

Implementation of the Cancer Delivery Plan

This refreshed delivery plan builds on the progress and successes to date. It provides continuity for the service up to 2020 and confirms a direction which is likely to endure beyond that timeframe. Where necessary, legacy actions have been taken forward but this cancer plan reflects the lessons learnt over the past three years and provides a greater focus on key areas where the most difference can be made.

The development of the plan has been led by the Wales Cancer Network and has involved extensive stakeholder input from across the health service and third sector. It also reflects new priorities which have emerged, such as prudent healthcare and the Wellbeing of Future Generations Act. This will significantly improve stakeholder buy-in and support collaborative working going forward.

An important development has been the bringing together of the north and south Wales cancer networks and the National Specialist Advisory Group into the Wales Cancer Network. Key clinical leadership and support mechanisms in one body will underpin cancer service improvement and place the patient at the heart of everything we do. Increasingly the Network is providing and coordinating the clinical leadership needed to draw people together and create synergies among different services, policies and projects.

Cancer pathways are delivered across many organisational boundaries – between primary, secondary and tertiary care; between health boards; between health boards and regional centres; with third and social care sectors; and in England for many people in mid and north Wales. With such a large and complex system, delivered by multiple professionals, teams and organisations, variation in practice and difficulties navigating the system must be overcome. This plan sets a common vision for cancer services in Wales and will help all those involved to work collaboratively to the same end.

It will be vital to build routine working relationships between the Network and health boards, specialist centres and the Welsh Health Specialised Services Committee. Increasingly important links will need to be developed with medical directors, directors of planning and cancer service leads. To realise its potential the Network will need to be integrated into this wider management structure of the health service and be seen as the 'go to' organisation for cancer specialist advice and service improvement in Wales.

⁷ Macmillan Cancer Support (2015) Statistics fact sheet
<http://www.macmillan.org.uk/documents/aboutus/research/keystats/statisticsfactsheet.pdf>

The national Cancer Implementation Group is accountable to the Chief Executive of NHS Wales for the overall coordination of the delivery plan implementation and acts as a forum for the development of national solutions to common delivery problems. Increasingly the Implementation Group is steering improvement activity rather than delivering projects as its delivery mechanisms mature. The Chair of the Group acts as a link to the all-Wales chief executives group and the NHS Collaborative.

The vast majority of resource, effort and potential reside with the health boards and trusts delivering cancer care. At the forefront of delivering the cancer plan will be the provider responses as detailed in their Integrated Medium Term Plans. The Implementation Group role is to support this local activity in the context of the national cancer delivery plan, supporting organisations to work regionally and nationally to meet standards, reform pathways and integrate services.

Key areas of focus are likely to be integrating the primary and specialist parts of the cancer pathway, supporting improved access and timeliness to diagnostics, improving productivity and capacity, as well as improving standards and supporting patients through and beyond active treatment. Continued close working between the Welsh Government, Cancer Implementation Group, Wales Cancer Network, Wales Cancer Alliance⁸ and care providers will be key to delivering this next phase of the cancer plan at greater pace and with greater impact.

The Cancer Delivery Plan aim is to close the gap with the best performing European countries by giving everyone with cancer the highest standard of care. This will be demonstrated through improving survival, reducing premature mortality and maintaining high levels of positive patient experience.

**Dr Tom Crosby, Medical Director
Wales Cancer Network**

⁸ Alliance of cancer charities in Wales

Preventing Cancer

It is predicted that by 2020⁹ half the UK population will develop cancer at some point in their lifetime. Much of this reflects the fact that people are living longer as half of cancers occur after the age of 66¹⁰. However individual risk factors vary and it is estimated that approximately 40%¹¹ of cancers are directly related to lifestyle behaviours. Smoking remains both the biggest challenge and opportunity to reduce people's risk but levels of obesity, harmful drinking and sun exposure also contribute heavily to increasing incidence of certain cancers.

Government has an important role in helping to improve the societal conditions that underpin these behaviours and has taken action such as tobacco control legislation and industrial disease protection to reduce exposure to harm and tackle the unequal burden of risk taking behaviour on society. Equally, local government and health services focus preventative efforts at areas of higher deprivation to help redress inequalities in cancer incidence and outcomes in the long-term. An extensive body of evidence already exists to support the types of interventions and policies which address the root causes of ill health and inequalities and lead to better mental, physical and social wellbeing together with enhancing resilience, employment and economic growth.

Many of the risk factors for cancer are common to other disease areas, such as cardiovascular disease; therefore it is clearly worthwhile having cross-cutting prevention strategies as well as those where there is evidence to support a targeted approach to a specific cancer. Wales has been proactive in tackling tobacco use and the revised Tobacco Control Delivery Plan will lead efforts in this area. Similarly, other programmes aimed at harmful drinking, physical activity and obesity will be led by Public Health Wales and local public health teams. Important interventions also include HPV and Hepatitis B vaccination; as well as work under the Liver Disease Plan to reduce Hepatitis C infection. Environmental protection interventions, including legislation on sunbed use and awareness programmes on radon gas, are also important levers to help reduce cancer incidence.

It is important to reinforce the need for people to take responsibility for their health and lifestyle in order to play their part in reducing their risk of ill health and alleviate an unsustainable level of demand on future health services. One element of this is for individuals to be knowledgeable about what the risk factors for cancer are and how to reduce them. Alongside this, the public sector, third sector and private sector should do all they can to enable and encourage people to lead healthier lives.

Many organisations are involved in delivering a comprehensive set of public health interventions and services. The cancer delivery plan seeks to complement and

⁹ Macmillan Cancer Support (2015) Statistics fact sheet
<http://www.macmillan.org.uk/documents/aboutus/research/keystats/statisticsfactsheet.pdf>

¹⁰ National Cancer Institute (2016) About Cancer
<https://www.cancer.gov/about-cancer/causes-prevention/risk/age>

¹¹ Cancer Research UK (2016) Statistics on Preventable Cancer
<http://www.cancerresearchuk.org/health-professional/cancer-statistics/risk/preventable-cancers#heading-Zero>

enhance existing initiatives by supporting approaches such as Making Every Contact Count and signalling their relevance to the cancer agenda. Public Health Wales, in collaboration with health boards, will have lead responsibility for these lifestyle interventions. It will be important for *all* clinicians to be aware and sufficiently skilled to support this agenda.

Key actions are:

1. Public Health Wales to lead a comprehensive prevention programme to minimise population-level risk of disease, including cancer. This will include taking opportunities to highlight lifestyle behaviours as risk factors for cancer.
2. Public Health Wales and health boards to continue to deliver HPV and Hepatitis B vaccination programmes as recommended by the Joint Committee on Vaccination and Immunisation and Wales Immunisation Group; and will await the JCVI recommendation on HPV vaccination for adolescent boys.
3. Health boards, through the Liver Disease Delivery Plan, to continue efforts to reduce the burden of Hepatitis C through national roll out of new interferon-free Hepatitis C antiviral drugs.
4. Local Authority Environmental Health Departments to continue to deliver their environmental protection activity minimising population risk of exposure to environmental contaminants such as air pollution and continue to enforce sunbed legislation.
5. Public Health Wales to continue to raise awareness of radon gas emissions.
6. Progress on tackling risk factors for cancer to be monitored and reported through the Public Health Outcomes framework by health boards and trusts.

Detecting cancer earlier

International studies consistently show Wales toward the bottom of international comparators for cancer survival and highlight late stage at diagnosis as a major causative factor. The significantly higher number of patients diagnosed in an emergency setting and the proportion of cancers diagnosed at later stages suggests Wales needs to better identify cancers at earlier stages. Detecting cancer early makes it more likely that treatment can be curative, less intensive and less expensive.

Population screening plays an important part in helping to detect cancer before symptoms appear and increases the likelihood of more cancers being identified earlier. Public Health Wales delivers screening programmes for breast, bowel and cervical cancers. The introduction of screening programmes in Wales is based on the expert advice of the UK National Screening Committee and Wales Screening Committee to ensure programmes do more good than harm and are cost-effective. However, for programmes to reach their potential the uptake of screening services by the public needs to improve and a combination of awareness raising and more acceptable testing will help to achieve this. Targeted action in areas of high deprivation, where it is known uptake of screening programmes is lowest, will also support a reduction in inequalities of health outcome. This must increasingly involve a range of local community services to improve awareness and public engagement with the national screening programmes.

The issues behind delayed cancer diagnosis are complex. International evidence points to a lack of public awareness of red flag ('alarm') symptoms and a lack of willingness to bother GPs; the challenge for GPs to identify cancers that present with non-specific ('vague') symptoms and a reluctance to refer onwards due to concerns about burdening stretched secondary care services. There are also unnecessary delays in the structure of the diagnostic pathway and additional secondary care gatekeeping and down-grading of referrals. This can contribute to reduced access, unacceptable delays and a poorer prognosis for patients. This underlines the need for better communication and support between primary and secondary care services.

It will be important to continue to improve symptom awareness among the public, a vital component of co-production and equalising the relationship between people and healthcare professionals. The Wales Cancer Network has delivered a lung cancer awareness campaign and further campaigns will have a part to play in helping to raise awareness of 'alarm' symptoms for cancers. GPs are alert to the possibility of cancer, referring around 80,000 patients a year for suspected cancer. However, many symptoms are not cancer specific and currently on average only 1-in-10 urgent referrals for suspected cancer will later be confirmed with a diagnosis of malignancy. In order to support primary care, it will be important to make available risk assessment tools, training materials and provide access to specialist advice.

The National Institute for Health and Care Excellence (NICE) has introduced guidelines which encourage more referrals in expectation of identifying more cancers at an early stage by lowering the recommended threshold of risk for a suspected cancer referral. The logical conclusion of the guideline is both an increase in referrals and a fall in the proportion of those patients referred who will actually be found to have cancer. It will be important for primary care to adopt the guideline and for diagnostic services to be developed to cope with the expected increased demand. Primary care should continue to reflect on management of patients diagnosed with cancer, building on the single event analysis approach set out under the National Priority Area in the GP contract for the prevention and earlier detection of cancer. Learning from this and the Framework for Cancer programme should inform primary care Cluster Action Plans.

A specialist multi-disciplinary team, representing the Cancer Implementation Group, visited Denmark to learn from a high performing healthcare system and diagnostic pathways are being rethought in light of learning from this visit. The Danish 'three-legged' system of referral: fast track pathways for patients with alarm symptoms, access to multi-disciplinary diagnostic centres for potentially serious, vague symptoms and direct access to certain tests for 'low-but-not-no' risk symptoms are key areas for pilot projects in Wales. These will require robust evaluation and processes to implement shared learning across Wales. Cwm Taf and Abertawe Bro Morgannwg University Health Boards are planning early pilots of diagnostic centres. However, it will be an enormous challenge in Wales to improve diagnostic access. This is related to the need for more imaging equipment and addressing workforce shortages in pathology, radiology and oncology, as well as reforming the way diagnostic pathways work. The National Imaging Programme Board's proposed development of an imaging academy and the wider NHS workforce strategy will be key levers for addressing the workforce shortages limiting access to diagnostic

testing. It is important patients are supported, that 'safety net' systems are in place and that information systems between primary and secondary care are in place.

Key actions are:

Public Health Wales

7. Public Health Wales to continue to deliver the national screening programmes for cancer and respond to recommendations on cancer screening from the UK National Screening Committee and Wales Screening Committee.
8. Public Health Wales to continue to work to improve screening uptake rates, with a focus on deprived communities where the benefit of screening is greatest.
9. Public Health Wales to introduce new and more effective primary screening tests in the cervical and bowel screening programmes.
10. Public Health Wales to work with the Wales Cancer Network to develop a programme of awareness campaigns for cancer.

Wales Cancer Network

11. The Wales Cancer Network, working through the Framework for Cancer, to support primary care clusters to utilise the significant event analysis approach to drive quality improvement through practice and cluster planning.
12. The Wales Cancer Network, working through the Framework for Cancer and the Diagnostic Services Programme, to support the implementation of the NICE referral guidelines.
13. The Wales Cancer Network to work through the Framework for Cancer, the Diagnostic Services Programme and specialist MDTs to deliver improved diagnostic pathways. This will include learning from the 'three-legged' Danish model, influencing clinical behaviours around gatekeeping and downgrading, and working with health boards to support pilot multi-disciplinary diagnostic centres and scope future roll out.
14. The Wales Cancer Network to extend the peer review programme to the primary-secondary care diagnostic interface.

Health boards

15. Education and awareness programmes, such as the oral cancer e-learning module, to be developed and rolled out to pharmacists, GPs and other registered health professionals as part of wider programme of awareness involving the Dental Deanery, Public Health Wales and Community Services.
16. The Endoscopy Implementation Group to continue to coordinate health board improvements in endoscopy access and service quality.
17. The National Imaging Programme Board to continue to develop capacity in diagnostic imaging services and the National Pathology Board will continue to develop capacity in pathology services.
18. The Genomic Strategy Task Force will continue to develop plans to develop the infrastructure required to support the Genomics and Precision Medicine Strategy

Delivering fast, effective treatment and care

Excellent service quality is an absolute commitment in this plan. This has a number of components, including referral to treatment times, early adoption of evidence based treatments, meeting national standards and integration of care pathways. This service quality needs to be demonstrated through national audit, challenged by national peer review and continuously improved through education, research and workforce developments.

Referral to treatment times are an important measure of quality, not just productivity, as all patients should start treatment within 62 days of being aware they are suspected of having cancer to give them the best possible outcomes. Health boards and Velindre NHS Trust must maintain their focus and improvement efforts to meet national waiting times targets. Work is under way to develop a single cancer pathway that will better reflect patient experience of the pathway and drive continuous improvement to overcome system delays. The Wales Cancer Network should increasingly support improvements in the performance of cancer services and help these services to plan and work together more effectively. In particular, the Network can support the systematic application of learning from successful pathway innovations across Wales.

Cancer services should be evidence based, taking into account NICE and other recognised national standards, and any variation from these standards must be fully justified. The Wales Cancer Network has an important role in helping services to tackle variation in standards and service quality. The Clinical Oncology Subcommittee (COSC), will deliver advice regarding radiotherapy quality standards across Wales (for example access to image guided, intensity modulated and stereotactic radiotherapy) but will also advise how services should network together and report against agreed quality performance metrics. A similar group will be established to oversee systemic anticancer therapies in Wales. Through participation in national clinical audit and the peer review programme, cancer services have the tools needed to understand how services are meeting quality expectations and the data to justify service improvement initiatives. Important new areas will be considered for peer review such as services for children and young people, rarer cancers and acute oncology services.

Multi Disciplinary Teams (MDTs) remain the cornerstone of patient management in secondary care and their evolution is a huge success in Wales. The potential to enhance their role as vehicles for governance and improvement will be explored. They should become the focus of the provision and analysis of performance data and respond consistently to the findings of audit and peer review. MDTs need to demonstrate real engagement with primary care to ensure general practitioners are supported by specialist services; referrals are efficient and appropriate, and ensure maximum patient benefit. This also includes supporting patients to face their treatment (pre-habilitation), the management of other illness they may also have, support through the complexities and complications of care (enhanced recovery programmes and acute oncology services) and preparation for their discharge after treatment (rehabilitation).

There should be equity of access to complex and very specialist care across Wales through close working between the Welsh Health Specialised Services Committee (WHSSC) and the Wales Cancer Network to better plan services. For example, COSC will work with WHSSC to ensure appropriate access to proton beam therapy for patients in Wales. In addition to WHSSC, there will be improved collaboration across organisational boundaries in the planning, commissioning and delivery of regional services. Patient pathways need to be improved and regional MDTs need to have clear governance and accountability arrangements in place to support this. In some cases focusing the expertise on fewer delivery settings, for example complex surgery or SACT delivery locations, will ensure sustainable access to affordable, enhanced, high quality services.

There are three oncology centres in Wales who share similar challenges and the three centres need to take a more consistent approach to care where appropriate. The centres need to consider their needs in terms of capital investment and their approach to the introduction of new treatments whether this be radiotherapy or systemic treatments in a coordinated and cost-effective way. In particular the oncology centres should provide the drive behind further enhancement of acute oncology, support for patients and management of the late effects of cancer. The three centres through the Wales Cancer Network will compare outcomes through a new performance framework and share best practice more readily through the creation of more formal links facilitated by the Wales Cancer Network. The regional service change programmes including the regional collaboration for health in south west Wales and the Transforming Cancer Services Programme in south east Wales are important opportunities to develop better, more integrated regional services.

Services should meet the different needs of the population. There is a need to ensure patients with metastatic cancer are quickly identified, have data collected and have full access to services and support to meet their specialist needs. Although childhood cancers are rare compared to cancer in adults, and have a higher cure rate after intensive treatment, they remain the commonest cause of death from disease among 1-17 year olds.¹² Even after successful treatment they can have major long term effects on a child's growth, development, mental health and ability to have families in the future. Every child and teenager must be cared for as part of a specialist service, with a secure transition to adult services and recording of relevant data. In addition, the particular needs of patients who live a long way from where their treatment is provided, or who attend hospitals in England for any part of their care, will need to be addressed as part of the work of cancer services. The whole issue of local access to services is one which must form a delicate balance between accessibility and access to high quality, sustainable services.

The Treatment Fund and the One Wales process for interim commissioning decisions will improve the timeliness and equity of access to cancer treatments in Wales. The review of the IPFR process will seek to reduce variation in practice by examining the definition of exceptionality, considering the optimal configuration of panels and the clinical behaviours around making applications. Finally, the era of precision medicines and the development of integrated genetics services have the potential to radically transform the delivery of cancer care. Wales must make the

¹² Public Health Wales. (2016) Child deaths in Wales. Patterns and trends report 2016. Cardiff: Public Health Wales NHS Trust

most of its world-leading genomics expertise to the benefit of patients through the implementation of the Strategy for Genomics and Precision Medicine.

Key actions are:

Integration

19. Supported by the Framework for Cancer, health boards to create formal links between primary care clusters and specialist cancer teams.
20. The governance arrangements for regional/specialist MDTs to be agreed between all the health boards and trusts involved.
21. The regional cancer centres, Wales Cancer Network and WHSSC to work together to ensure equity of access and delivery of service quality
22. Health boards to take advantage of the ARCH and TCS programmes and provide regional models of delivery, innovation, integrated pathways, create economies of scale and provide more specialist treatment closer to the patient's residence.

Quality

23. The Wales Cancer Network site groups to develop site-specific service specifications, advise on appropriate service configurations (where appropriate through specific reviews (e.g. WHSSC's thoracic surgery review) and prioritise and lead service quality improvement programmes
24. Health boards and trusts to continue to participate in national clinical audit for cancer and an extended peer review programme, based on a new performance framework, using the findings to monitor service quality and develop improvement plans.
25. Health boards to further develop acute oncology services, ensuring they comply with national standards and work to expand them to 7-day provision.
26. Health boards to ensure patients with metastatic disease receive care and support appropriate to their needs, through improved collection of information on the care provided and a focus for peer review delivered by the Wales Cancer Network.
27. All Wales Therapeutics and Toxicology Centre to continue to undertake horizon scanning to support the NHS in planning for the prompt introduction of cost effective cancer medicines.
28. AW TTC to facilitate improvements in the IPFR process, and support a more consistent approach to the availability of medicines not appraised by NICE or All Wales Medicines Strategy Group through the One Wales commissioning process.
29. Welsh Government to undertake a review of IPFR and implement the agreed recommendations.
30. Welsh Government to develop and implement a Genomics and Precision Medicine Strategy for Wales.

Performance

31. Health boards to continue to monitor performance against national waiting times targets and focus on improving performance.

32. Health boards to ensure cross border flows do not disadvantage patients in access to treatment and care.
33. The Wales Cancer Network will continue to work with health boards to explore the introduction of a single cancer pathway and consider component waits within a new cancer performance framework.

Meeting the needs of people affected by cancer

Successive national cancer plans have highlighted the importance of person-centred care and this continues, perhaps with greater emphasis than previously, under the prudent healthcare approach. Individualised care is the aim for all treatment and care service providers; particularly where the benefits and harms of treatment are closely balanced. This is underpinned by a broader commitment to dignity in care throughout all services.

An analysis of the 2013 cancer patient experience survey free text comments highlighted that perceived time delays in the pathway can cause distress. They also describe the transition points of referral into and discharge from the acute treatment phase as being one of particular vulnerability. Alongside the pressures of referral to treatment times, there is an understandable tendency to prioritise urgency given the aggressive nature of many cancers. This can pose challenges for having time for a more informed and considered discussion between clinicians and patients about treatment options and goals. Co-production is about individuals agreeing a joint set of actions appropriate to their values and to achieve their personal expectations of care. It is also important to take time to liaise with the GP on the management of co-morbidity, to prepare the patient through structured education approaches and to consistently apply key interventions such as holistic needs assessment, allocation of a key worker and the provision of an ongoing care plan. Much progress has been made in these areas but a lack of consistency across Wales needs to be addressed.

The 2013 cancer patient experience survey also showed patient experience is exceptionally high, albeit with significant variations by cancer type. It demonstrated the important difference key workers can make to a person's experience of cancer services. The cancer pathway is complex and a named key worker is fundamental to help the patient navigate the pathway and ensure a smooth patient journey. The key worker is usually the clinical nurse specialist, who as part of a wider multi-disciplinary team coordinates treatment and care. The healthcare system, and patients, should also be clear who their responsible doctor is at all stages of the care pathway.

Other areas of learning include the importance of post-treatment support and helping to avoid people feeling unsupported by the system when their treatment ends. The increasing number of people living with the impact of cancer is both an enormous success and a big challenge in terms of meeting people's needs for post-treatment support and follow up. The Social Services and Wellbeing Act requires health services and local government to work together to develop services to meet people's needs. Primary care services in particular will need to be ready to support patients with the complications of their treatment – both psychological and physical. The Framework for Cancer has a strong focus on survivorship and supporting primary care to better meet the needs of people who have finished their treatment. Effective discharge planning and discharge summaries are vital pre-requisites and

consideration should be given to all providers applying a common recovery package. The appropriateness and variability of follow up arrangements needs consideration on an all-Wales basis and should be delivered in a more personalised, responsive to need and risk-stratified way.

Cancer is in fact around 200 diseases and every person's experience of cancer is unique. Individual clinicians and services need to be aware and responsive to individual pieces of feedback and learning. As a health system, services need mechanisms to identify common issues and themes of patient input to steer service development. The Cancer Implementation Group, working with Macmillan Cancer Care, is delivering a second national survey to support health board quality improvement and is committed to continuing to learn from patient experience and outcomes by exploring the potential for more regular and embedded Patient Reported Experience Measures (PREMs) and Patient Reported Outcome Measures (PROMs). The Wales Cancer Alliance, which brings together the main national cancer charities, should work with the Wales Cancer Network to consider how best to systematically use patient experience to shape healthcare services for people affected by cancer. Community Health Councils should also work with the Network to monitor health board compliance with agreed action plans.

Access to services has been noted as a challenge and services should be provided as locally as is feasible, with health boards providing support for transport and accommodation as appropriate. Some services are appropriate to deliver via mobile units and the third sector plays an important role here. Benefits advice services are a vital means of supporting people with the financial hardships caused by cancer and a number of organisations provide these services. There is potential to maximise impact by considering joint working and coordination. Patient experience among children and young people, as well as among metastatic patients, is not as well understood as experience for other patients and will be considered further to ensure care is equitable. Health boards should work with the Wales Cancer Network to ensure coordinated telephone advice and support 24 hours a day, seven days a week.

Key actions are:

34. The Cancer Implementation Group to deliver further patient experience surveys and develop a longer-term approach to embedding patient reported experience outcome measure tools into service design, delivery and improvement.
35. The Wales Cancer Network to lead on the consistent application across Wales of elements of the 'recovery package' as appropriate to identified needs (e.g. key worker, electronic holistic needs assessment, care planning, education and structured support programme)..
36. The Wales Cancer Network to evaluate MDT person-centred skills, specifically communication and palliative care, and develop and implement an action plan
37. Health boards to ensure all patients are routinely informed where to access welfare benefits advice, .
38. Health boards to offer timely, high quality and accessible information about specific cancers and treatments; this will include pre-diagnosis supporting information, information on complexities and complications of treatment and

information on how to access care and support wherever they are in the cancer pathway.

39. Health boards to establish routine liaison mechanisms between primary and specialist care to meet people's ongoing and post-treatment care needs and ensure seamless handover between primary and secondary care.
40. Where possible health boards should provide care locally and support patients who need assistance to travel or stay away from home.

Caring for people with cancer at the end of life

Some patients may feel the pressure of battling and surviving cancer requires them to undergo additional rounds of intensive treatment which undermines their quality of life. This is particularly relevant when receiving palliative and end of life care. It must also be acknowledged that a patient's feelings and wishes will change over time and should be regularly considered to inform the treatment plan. A more honest and open discussion regarding treatment outcomes and side-effects needs to be continually encouraged to ensure patients can make informed decisions as part of their co-produced care.

There is increasing evidence that integrating palliative care support within the patient pathway can improve quality of life and in many cases quality of death; as well as in some cases prolong length of life. This approach can also support a more balanced discussion about the benefit and harms of anticancer therapy towards the end of life. The wider approach to the prudent use of interventions being taken forward under the banner of Choosing Wisely can only be achieved where patients are empowered with balanced and understandable information regarding their treatment options.

The importance of palliative care services has been recognised and is led through the End of Life Care Plan and Palliative Care Implementation Board. Important contributions are also made from the Byw Nawr (Living Now) group and cross-group working with the End of Life Care Implementation Group is to be established. Palliative care services are a notable success story in Wales but the skills involved in supporting patients in terms of palliative care need to be spread throughout cancer services.

Key actions are:

41. The Wales Cancer Network to support training palliative care programmes, including for GPs and nursing home staff, nurses and allied healthcare professionals.
42. Health boards to plan, secure and deliver well coordinated palliative and end of life care on a 24/7 basis in line with published standards and guidance.
43. Health boards to ensure DNACPR (Do Not Attempt Cardio Pulmonary Resuscitation) decisions are discussed with the patient and family and recorded.
44. Health boards to support all providers who care for dying patients to participate in the all Wales audit of the care decisions documentation.
45. Health boards to have clear funding streams for specialist palliative care services which are above the minimum levels advised by the End of Life Board.
46. Health boards to support patient and carer self-management programmes.

47. Health boards to encourage the initiation of Serious Illness Conversations with patients and their families, enabling informed decision-making on treatments and investigations.
48. Health boards to encourage shared decision making with patients including benefits of maximising a conservative treatment approach, if patient preference is to forgo intensive systemic anticancer treatments
49. Health boards to establish and prioritise people's preferences for place of death, including having first and second preferences of place of care, so unexpected outcomes and symptoms can be understood and accommodated.

Improving cancer information

Intelligence from comprehensive and reliable information informs services, clinicians and patients to improve outcomes. A Cancer Information Framework, aligned with Wales' Digital Health and Care Strategy, is required to set out what information and intelligence is needed, as well as how mechanisms will deliver this information to inform and evaluate improvement.

Clear information is a key aspect of a high quality service for patients. Quality, accessible information about their condition and treatment options supports people to participate in shared decisions about their care. Patients must also have clear treatment plans to guide them through what can be very complex care processes. Increasingly patient should be able to access their own clinical records and interact digitally with the health service.

Usable, comparable and timely information on health service activity and performance, along the cancer patient's pathway, needs to be available on an all-Wales basis. Its interpreted analysis and reporting (increasingly automated) can then help inform service planning, quality improvement and performance efforts against national standards. These cancer intelligence metrics will form the basis of a new cancer performance framework. A common pathway monitoring tool is being made available to health boards to monitor the waits involved in each stage of the pathway to support pathway innovation and improvement projects. A critical informatics requirement for Wales is interim additional functionality, alongside CaNISC, to support patient multi-disciplinary team management and participation in national audit. This will allow services space to develop and adopt a successor to the patient management system as part of the national informatics architecture.

Common informatics platforms will better support more integrated care between organisations and reduce the potential for unnecessary harm. Important elements of this will include all providers moving to common national platforms to enable the consistent, automated and timely exchange of information. Adoption and incremental improvements to the Welsh Patient Referral System will help to transform the referral and management of patients through different parts of the system; from primary through to tertiary level services. Common pathology and imaging systems, while having experienced delayed roll outs, are starting to demonstrate the potential for joined up services and collaborative working.

Systems also need to provide information for public health purposes, such as population-based cancer registration and for research to improve targeting of

prevention and treatments. Population-based cancer registration (PBCR) is a well-established endeavour internationally. In Wales, a high quality PBCR is operated by the Public Health Wales Welsh Cancer Intelligence and Surveillance Unit (WCISU). It systematically collects quality-assured information on all defined new cases of cancer in a geographically-defined population from multiple data sources. This allows population cancer incidence, mortality and survival rates to be calculated and compared over time and with other populations. WCISU is modernising its cancer registration system and working with clinical data providers to increase and improve the datasets it receives. This has allowed valuable research into how cancer outcomes in Wales compares with other countries and insight into how things can be improved.

Key actions are:

Wales Cancer Network

50. The Wales Cancer Network to develop a Cancer Information Framework that aligns with the four Digital Health Strategy principles.
51. Wales Cancer Network will support health boards to improve patient access to their clinical data and the creation of a digital relationship between patients and healthcare professionals

Health boards and trusts

52. Health boards, NHS Trusts and regional/national cancer services to move as soon as possible to national platforms, including Welsh Clinical Portal (Welsh Results and Reports Service, Welsh Care Records Service) and the National Picture Archiving and Communication Systems (PACS).
53. Health board and trust cancer teams to adopt SNOMED Clinical Terms to improve consistency of clinical coding.
54. Health boards to adopt where feasible Tracker 7 to monitor component waits and support pathway improvement initiatives.
55. Velindre NHS Trust and the Wales Cancer Network, working in partnership with NWIS, Public Health Wales and health boards to coordinate the development of a permanent solution to the replacement of CANISC.
56. NWIS, working with the Wales Cancer Network and Public Health Wales, to develop an interim solution to limitations in CaNSIC functionality to participate in clinical audit and record staging information.

Public Health Wales

57. Public Health Wales, through its Welsh Cancer Intelligence and Surveillance Unit (WCISU), to implement a new cancer registration system with data provider feedback tools.
58. WCISU to continue to develop a cancer data repository with new datasets for cancer intelligence and research in collaboration with academic institutions such as the Farr Institute Swansea University Secure Anonymised Information Linkage (SAIL) Databank.
59. WCISU to develop a Memorandum of Understanding for collaborative working in relation to cancer intelligence needs with the Welsh Cancer Network.

60. WCISU to continue to develop its dashboard of population statistics and other key metrics.

Targeting cancer research

Cancer research is critical to improve outcomes for patients and for the health of people in Wales. Excellent research delivers high impact outputs that change future cancer understanding, treatment and care interventions across the whole breadth of the patient pathway, from primary through to palliative care.

People in Wales affected by cancer should have equitable access to participate in clinical trials and other well designed studies, including opportunities to be involved in and engaged in research activities. This will necessitate improved collaboration between Welsh NHS organisations to enable successful cross-organisation research delivery. This should ensure that the funding for studies allocated between health boards and trusts drives improvements in research activity, rather than the converse.

Research needs to be conducted in both the primary and secondary care settings, from cancer prevention, diagnosis, treatment, through to end of life care, and across multiple cancer types, including rarer cancers. Cancer research should align to the different challenges and priorities for these types of cancer as well as the patient clinical needs necessary to deliver an excellent cancer service.

The NHS in Wales plays a central role in improving cancer care through research. Having an embedded active research culture brings real benefits to patients and NHS organisations, including:

- Providing patients with access to novel therapies and cutting edge care interventions (eg early phase, biomarker driven, drug-radiotherapy and immunotherapy trials)
- Accelerating the adoption of novel therapies and treatment techniques, and raising the standards of routine care through detailed protocols and quality assurance programmes
- Development of biomarker testing to allow delivery of precision medicine, tailored to individual patients
- Providing opportunities for NHS staff of all disciplines to develop skills and gain experience of delivering innovative treatments and interventions, which is fundamental to attracting and retaining first class NHS staff in Wales
- Assisting organisations in the planning and delivery of their services, ensuring that research results translate into evidence based practice
- Encouraging research investment into the NHS and financial investment into Wales
- Strengthening partnership working with other NHS organisations, Higher Education Institutions, charities and pharma to support and lead the development of high quality research.

Cancer patients in Wales have demonstrated their willingness to give consent for their cancer tissue to be used for cancer research. This is in the hope, if not expectation, that the system will learn from their experience and improve outcomes

for future patients. Whilst the strategy for cancer biobanking may change eg towards targeting specific patient cohorts and researching 'longitudinal' samples to explore how patients malignant disease changes over time, the concept of the service supporting the current and future Welsh research community through cancer tissue collection, should continue to be supported.

In the 'Science for Wales' strategy, the Welsh Government identified cancer as an area of research strength in Wales. Through Health and Care Research Wales, the Welsh Government supports several major cancer related initiatives via the Wales Cancer Research Centre (which includes the Wales Cancer Bank) and the Wales Gene Park. Health and Care Research Wales continues to work with other UK funders to maximise the opportunities for Welsh researchers to apply for funds to support their cancer research programmes. Health and Care Research Wales works with NHS Wales to support and increase the number of cancer studies in Wales affording more research opportunities for people affected by cancer.

Key actions are:

61. NHS Wales should aim to develop a Welsh Cancer Research Strategy, reflecting the priorities and ambitions of patients, charities, NHS organizations, Universities, pharma and Welsh Government, which will provide a common goal for cancer researchers in Wales for the next 10 years
62. Health boards and Velindre Cancer Centre and Wales Cancer Research Centre (WCRC) supported by Health and Care Research Wales' workforce delivery, to increase the number of commercial and non-commercial cancer research studies undertaken in Wales.
63. Health boards and Velindre Cancer Centre to promote the importance of R&D by providing a platform for staff of all disciplines to engage and participate in research, encouraging and supporting protected research time.
64. WCRC, health boards and Velindre Cancer Centre to support the development of Wales-led cancer clinical trials and other well designed studies and in doing so ensure research governance. Health boards should seek opportunities to maximise the investment available through research.
65. Health boards and Velindre Cancer Centre to identify leads to ensure arrangements are in place so that research results feed into organisations' mechanisms for uptake of best practice and service change.
66. Wales Cancer Research Centre to consider opportunities to further develop partnerships between NHS organisation, academia, pharmaceutical companies and the third sector to facilitate timely application of research into the NHS.
67. Health boards and Velindre Cancer Centre to encourage the targeted consenting patient donations to the Wales Cancer Bank.

Cancer service performance and plan delivery

The increasing level of demand, cost and complexity of healthcare must be acknowledged. This is not an issue confined to cancer and the health service in general is facing enormous challenges and pressures. To improve cancer services and implement the delivery plan in this context is challenging but it must be driven forward nonetheless. All stakeholders and partners are committed to improvement in

cancer services and this plan provides a common vision and set of actions for the different providers and partner organisations to work toward.

Achieving full implementation of the first delivery plan was a major challenge as health services responded to huge levels of demand and multiple strategic drivers. However, the delivery plan methodology is now embedded in the working of the health service and increasingly aligned with Integrated Medium Term Plans. In addition, the attempt to implement the plan by establishing a national Cancer Implementation Group has now matured into a proper delivery board – which has moved beyond awareness and projects – towards becoming a real system driver of cancer services. This is enhanced by the unification of the cancer networks and NSAG into one all-Wales go to organisation for cancer improvement and advice, the Wales Cancer Network. The allocation of £1m annually to the implementation group is an resource to innovate and support national improvement through the national projects delivered by the Implementation Group.

There is an opportunity to implement the next phase of the delivery plan more effectively and at greater pace. There is also now greater clarity, focus and detail of what needs to be done and who will lead the work. The Cancer Implementation Group and Wales Cancer Network have facilitated the emergence of clinical leadership at an all-Wales level for cancer services. The delivery plan framework has also changed the way cancer services are considered by creating more meaningful all-Wales collaborative working between the health boards and trusts. It has provided a forum to link in with new developments such as primary care cluster working and harness the knowledge and input of the third sector through the Wales Cancer Alliance.

It will be important to make the most of the hard learnt lessons of the past three years, building on the current potential of the delivery infrastructure by integrating it formally into health board service planning and performance structures. In addition, revised implementation group reporting arrangements will maintain transparency but streamline process – the Implementation Group will provide annual assurance to the NHS Chief Executive on the delivery of the plan and implementation group will be able to link into the all Wales NHS quality and performance mechanisms. The Chair of the Implementation Groups will also have an important all-Wales role in terms of interaction with the NHS Collaborative and chief executive all-Wales group.

A key result of extending the current approach will be the consistency for services provided between 2013 and 2020. It is highly likely the main themes of the plan, such as standards, pathway integration, early detection and person-centred care, will endure beyond even that timeframe. The importance of a long-term approach to improving cancer outcomes is evidenced by practice in other countries.

Key actions are:

68. The Cancer Implementation Group to steer the implementation of the plan by creating more formal and systematic links with health boards and trusts.
69. The Cancer Implementation Group to provide direction to the Wales Cancer Network; as part of the NHS Wales Collaborative.

70. The Cancer Implementation Group to allocate £1m annually and report to the NHS Chief Executive annually on delivery plan implementation.
71. The Wales Cancer Network to work with health boards and Velindre NHS Trust to create a cancer performance framework for Wales.
72. The Wales Cancer Network to develop routine links into health board and trust cancer service improvement, performance and planning systems to support collaboration and catalyse improvement through national projects.
73. The Wales Cancer Network to provide expert advice on standards and service development to Welsh Government, the Cancer Implementation Group, the AWTTTC and AWMSG, as well as health boards and trusts.
74. The Wales Cancer Network to develop a Quality of Life Measure.
75. Welsh Government to continue to maintain oversight of delivery and assurance framework and produce national statement of achievement annually.
76. Welsh Government to support and enable liaison between the Implementation Group and Welsh Ministers.

Population Outcome Measures:

- Cancer incidence and prevalence
- Short and long-term survival rates
- Premature mortality related to cancer and mortality.
- Global Patient Reported Experience Measures (inc Cancer Patient Experience Survey)
- Global Quality of Life measure (to be developed)

Service Measures

Domain	Measure
Preventing Cancer	<ul style="list-style-type: none"> • HPV and Hep B Vaccination rates • Smoking cessation rates • Public Health Outcomes Framework
Detecting cancer quickly	<ul style="list-style-type: none"> • Stage at diagnosis • Emergency presentations • Screening uptake
Delivering fast, effective treatment and care	<ul style="list-style-type: none"> • Referral to treatment time • Compliance with national quality standards • 30-day mortality post treatment
Meeting People's Needs	<ul style="list-style-type: none"> • Allocation of key worker • Completion of electronic holistic needs assessment • Offer of a written care plan
Caring at the End of Life	<ul style="list-style-type: none"> • Preferred place of death • % advanced care plan in place
Improving Information	<ul style="list-style-type: none"> • CPES [longer term PREMs and PROMs] • Audit and Peer Review Participation
Targeting research	<ul style="list-style-type: none"> • Number of cancer clinical trials and research studies • Patient recruitment to cancer clinical trials and research studies • Consent to tissue donation (TBD)