

# Can earlier symptomatic diagnosis improve cancer outcomes in Wales?

## A report for Public Health Wales

Professor Richard Neal  
On behalf of North Wales Centre for Primary Care Research, Bangor University

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### Executive Summary

The incidence of cancer continues to increase in Wales, and is higher than in England. Cancer survival in Wales is improving with over half of patients surviving at least five years. One key factor in trying to improve survival is earlier diagnosis. The remit of this report therefore was to produce a plan to improve cancer outcomes in Wales through earlier diagnosis. This report is based upon a narrative review of the evidence and policy documents. The report is structured by bringing together different strands of policy, evidence and initiatives from Wales and internationally.

The Welsh Government Cancer Delivery Plan recognises that rapid diagnosis and treatment improves survival and quality of life and lessens survivors' longer term care needs, and that GPs are crucial in the process of diagnosing cancer timely, and that diagnostic testing, particularly must be available wherever this will reduce time to diagnosis. It also mandates Health Boards in Wales to undertake and report a number of cancer specific diagnostic measures. The Macmillan Primary Care Oncology Initiative will support GPs in cancer diagnosis. Modules of the International Cancer Benchmarking Partnership (ICBP) have provided comparative data concerning cancer awareness, GPs' diagnostic processes, and diagnostic pathways.

There now appears to be a consensus, supported by systematic review evidence, that there are benefits to clinical outcomes for more timely diagnosis in some cancers. These findings support previous assertions that at least a proportion of the 'lives lost' can potentially be prevented by earlier diagnosis. In other countries there have been specific initiatives to diagnose cancer more quickly. For example there has been a 'National Awareness and Early Diagnosis Initiative'. In Scotland there has been a 'Detect Cancer Early' Campaign. There have been no specific initiatives or campaigns in Wales.

There are a number of ways in which the earlier diagnosis may be achieved. These include:

**Reducing times to presentation of symptoms by increasing public awareness of potential cancer symptoms and appropriate advice about when and how to see a doctor or health professional**

**Reduction times from first presentation of potential cancer symptoms to referral or diagnostic investigation by GPs**

**Hastening diagnosis through system change (for example by increasing access to diagnostics and reducing waiting times)**

**Reducing socioeconomic, age and gender inequalities in the diagnosis of cancer.**

A number of recommendations for Welsh Government, Public Health Wales, Health Boards are made along with some research recommendations.

## Recommendations for Welsh Government

- To make the early diagnosis of cancer a governmental priority. One way of doing this would be to support the development and activity of a Welsh Awareness and Early Diagnosis Initiative (WAEDI), or similar.
- To consider adopting a similar approach in Wales to that developed in Denmark for the assessment of patients with symptoms.
- To support ongoing and future initiatives aimed at increasing cancer awareness, for all cancer types in Wales.
- To support the participation of Wales in modules of Phase 2 of the International Cancer Benchmarking Partnership

## Multi-agency Recommendations

- To support ongoing and future initiatives aimed at increasing cancer awareness, for all cancer types in Wales.
- To develop routine linkage of GP data via Audit+ to the WCISU cancer registry.

## Recommendations for Health Boards

- To support ongoing and future initiatives aimed at increasing cancer awareness, for all cancer types in Wales.
- To fully engage primary care staff with issues regarding cancer diagnosis through primary care, and provide resource for timely diagnosis.
- To provide wider and faster access for diagnostic investigations and specialist opinion from primary care.
- To streamline diagnostic pathways for all patients with potential symptoms of cancer (whether 'Urgent Suspected Cancer' or otherwise).

## Recommendations for Research

- To seek further funding for proposals regarding the public awareness of cancer symptoms in Wales.
- To seek further funding for proposals to expedite and maximise the efficiency of cancer diagnosis through primary care in Wales.
- To seek funding for proposals aimed specifically at the 'harder to diagnose' cancers and those cancer types with a higher incidence and poorer outcomes in Wales (for example, lung, brain, myeloma, upper gastro-intestinal).
- To seek funding for a proposal that aims to fully evaluate the health economics of earlier cancer diagnosis in Wales.

## 1. Introduction

### 1.1. Remit and purpose of this report

This report has been commissioned by Public Health Wales. The remit of the commission is to produce a plan to improve cancer outcomes in Wales through earlier diagnosis. This plan will outline a number of initiatives, based upon best available evidence, for the next 3-5 years. The focus of this report is on the earlier diagnosis of symptomatic cancer. Hence, issues to do with: screening and the delivery and uptake of screening programmes; biomarker development; chemoprevention strategies; and lifestyle modification to change risk of cancer are outside the remit of the report. The exact terms of the 'deliverable' as outlined in the commissioned are included in Appendix 1.

### 1.2. Methods & structure of this report

This report is based upon a narrative review of the literature and policy documents. The lead author is familiar with this body of literature, and of research activity (in the UK and internationally) in this area for the past decade. The report is structured by bringing together different strands of policy, evidence and initiatives from Wales and internationally. These are a presentation of cancer incidence and outcomes in Wales; and a discussion of the NHS in Wales in relation to cancer diagnostics. This is followed by a discussion of the evidence that timelier diagnosis leads to better outcomes, a discussion of the various ways in which earlier diagnosis may be achieved, and a summary of what initiatives are happening in Wales and in other similar countries to achieve earlier diagnosis. These themes will then be brought together to present that potential for future initiatives to expedite cancer diagnosis in Wales, and a series of recommendations for policy, practice and research.

### 1.3. Definitions

Throughout this report, the term 'earlier diagnosis' is used to mean 'earlier **stage** diagnosis', rather than more 'timely' diagnosis *per se*. However, more timely diagnosis is often associated with earlier stage diagnosis (this will be discussed in Section 4). 'Outcomes' primarily refer to survival / mortality, but also to stage shift (in effect a proxy for survival) as more favourable stage at diagnosis allows better treatments and better survival. Other definitions, especially relating to time intervals in diagnosis, are reported in line with the recommendations of the 'Aarhus Statement' on the reporting of studies on early cancer diagnosis (Weller, 2012).

### 1.4. The importance of report

As will be demonstrated in the report, Wales, along with other UK countries has some of the worst cancer outcomes in Western Europe. It is widely accepted that delayed diagnosis is at least part of the problem (Richards, 2009), and therefore any solutions that improve early diagnosis are likely to improve cancer outcomes. It has been estimated that in the UK, 5000-10000 deaths within five years of diagnosis could be avoided annually if efforts to promote earlier diagnosis and appropriate surgical treatment are successful (Richards, 2009). Crudely, extrapolating these figures to Wales equates to 300-600 deaths annually. How this equates to quality of years gained (rather than just living longer with cancer by diagnosing earlier) is unclear at present. Aside from survival outcomes, earlier diagnosis has other benefits including: improving the patient diagnosis experience; a benefit on non-cancer diagnoses; reducing treatment burden and co-morbidity; and decreasing medico-legal and

other complaints (Lyratzopoulos, presented at NAEDI conference 2015). There are also potential harms in terms of potential guilt / regret / anxiety of potential missed early diagnosis in cases where it may not have made a material difference. This report aims to set the agenda for future cancer priority over the next 3-5 years through a number of recommendations for implementation and research.



## 2. Cancer in Wales

Recent statistics have been released regarding the incidence, mortality and survival for cancer in Wales (Welsh Cancer Intelligence and Surveillance Unit, 2015). Key data and trends are summarised below.

### 2.1. Incidence

- For the 10 years up to, and including, 2013 the incidence of cancer cases in Wales slowly increased
- Peak age for cancer incidence; men – 75-79 years and women – 80-84 years
- There has been a large increase in incidence in both genders after 85 years, which is attributed to the increase in the number of people in this age group
- Incidence is similar for both genders up until 55-59 years with much higher rates for men in older age groups
- Age-standardised cancer incidence in males is about 5% higher in Wales than in England (House of Commons Library, 2014)
- Once population sizes and age structure in different geographic areas of Wales have been taken into account there is considerable variation in the age adjusted cancer incidence per 100,000 in the population

### 2.2. Cancer types

- The most common cancer types in Wales are breast (women), prostate, lung, and bowel. This is comparable to Europe more generally (Ferlay, 2013)
- Prostate cancer accounted for over a quarter of all cancers in men. Bowel and lung cancer each accounted for one in seven cancers in men
- Breast cancer accounted for a third of cancers in women. Lung was the second most common accounting for almost 12%. One in ten new cancers in women was bowel cancer
- Prostate, bowel, breast (women), melanoma, and lung cancers had the largest increase in numbers. Cervical, oesophageal and stomach cancers showed decreases in numbers
- Largest increases in incidence rates for men from 2001-2001 to 2011-2013 were melanoma, head and neck, urinary tract excluding bladder, liver, prostate and bowel. There were large percentage decreases in stomach, lung and oesophageal cancer
- Lung cancer shows the largest increase rate over the same time period. Next largest were breast (women), uterus, melanoma, bowel, urinary tract excluding bladder, and liver cancer. Largest percentage increases were liver, urinary tract, melanoma, uterine, thyroid and endocrine, head and neck, and lung. Notable percentage decreases in stomach, oesophageal, cervical, and brain and central nervous system (CNS). In Wales, rates of male skin cancer are 28% higher than UK wide rates (House of Commons Library, 2014)
- Liver cancer in men showed the largest percentage increase in men. For women, liver cancer increase in numbers was as much as 70%
- Melanoma showed the second largest percentage increase. Number of cases in men nearly doubled, and increased by half in women

### 2.3. Mortality

- There were 8,688 cancer deaths in Wales during 2013 compared with 8,484 in 2004
- There was considerable variation between health boards. Powys Teaching Health Board had an age adjusted mortality rate 10% lower than Wales as a whole and Cwm Taf University Health Board had a mortality rate 8% higher than Wales as a whole
- Betsi Cadwaladr University Health Board had the largest number of cancer deaths in 2004 and 2013, due to having the largest population and a large proportion of older people

### 2.4. Survival

- 70% of Welsh residents can now expect to survive at least one year after a cancer diagnosis
- One year relative survival is similar across all seven health boards
- One year survival is beginning to increase but this increase is slower now than in earlier years
- Over half of Welsh residents diagnosed with cancer survive for at least five years
- Five year survival is also increasing but more slowly than in earlier years
- Many factors may affect survival; type of cancer, earlier diagnosis, general health, patient age, improvements in effective treatments, participation in screening
- One year relative survival for all cancers combined has improved in all deprivation fifths over time but the increase is greater in the most deprived fifth than the least deprived fifth thus narrowing the gap; however a greater increase in five year survival is seen in the least deprived fifth compared to the most deprived fifth over time, widening the gap
- Cancers with lowest one year survival are pancreas, lung and liver for both time periods examined.
- Testicular cancer has the highest one year survival rate with 98% followed closely by melanoma, prostate and breast (women) cancer (all over 96%)
- Lowest five year survival rates were for pancreas, liver, and lung cancer

### 3. NHS Wales structure and policy-making in relation to cancer diagnostics

This chapter aims to briefly present the structure of the NHS in Wales in relation to cancer diagnostics, and key policy initiatives. The purpose of this is to demonstrate who has responsibility and accountability for certain issues, and to identify where changes or interventions need to be directed in order to facilitate earlier diagnosis.

Health is a devolved function of government from Westminster and has been since 1999. Health reforms in Wales in 2009 led to a reorganisation of the NHS into seven Health Boards and three NHS Trusts. Welsh Government is responsible for strategic leadership through setting the health outcomes it expects for the people of Wales and holds the NHS to account on how well it delivers its outcomes. Lines of accountability are via the Chairs of the Local Health Boards and Trusts to the Minister for Health and Social Services. The Chief Executives of the Local Health Boards and Trusts report to the Chief Executive of the NHS Wales (who is also the Director General of the Welsh Government's Department of Health Social Services and Children).

Local Health Boards (LHBs) are responsible for planning, securing and delivering local services to help prevent cancer and to diagnose, treat and care for people affected by cancer. All seven LHBs plan and fund specialist cancer services through their partnership work on the Welsh Health Specialised Services Committee (WHSSC). Velindre NHS Trust hosts the National Wales Informatics Service (NWIS), which supports LHBs in the collecting and reporting of information. This includes the Cancer Information System Cymru (CaNISC) where clinical patient information is recorded.

The two former Cancer Networks (South Wales and North Wales) are now merging into one, and work in partnership with LHBs, Trusts, Community Health Councils, Voluntary Organisations and Public Health Wales to co-ordinate the planning, organisation and delivery of cancer services within their defined geographical area.

The National Specialist Advisory Group for Cancer (NSAG) provides all Wales clinical specialist advice on cancer in Wales. It currently supports an executive group and nine cancer sub-groups as well as the Welsh Government's Cancer Implementation Group (CIG) and its sub-groups. Advice is provided in response to requests from the CIG, the Cancer Networks and other all Wales organisations such as Welsh Health Specialised Services Committee (WHSSC) and All Wales Therapeutics and Toxicology Centre (AWTTC) for LHBs.

The All Wales CIG provides joined-up leadership and oversight and aims to co-ordinate action in a strategic way. It aims to support LHBs to deliver the outcomes asked of them in a consistent way across Wales, to agree how best to measure success, to facilitate the sharing and implementation of best practice, and to identify constraints and solutions to common issues where a strategic approach is needed.

Public Health Wales provides LHBs with information and advice to inform service planning. It also provides the Wales cancer registry through its Wales Cancer Intelligence and Surveillance Unit (WCISU). It is committed to 'improving health and wellbeing and reducing health inequalities' which includes 'interventions focused on cancer' (Public Health Wales, 2014).

Local Government has a role in that it works with LHBs (via local service boards) to provide a co-ordinated approach. This work includes the analysis of the evidence base and development of Single Integrated Plans showing how they can contribute to improving health outcomes (in areas such as smoking, obesity, nutrition and exercise).

The Third Sector has an important role to play in providing services, funding research and acting as the voice of individuals. The Cancer Alliance grouping can help both inform policy and provide an independent overview of progress.

### 3.1. The Welsh Government 'Cancer Delivery Plan'

This was published in 2012 and is intended to be 'a framework for action by Local Health Boards and NHS Trusts, setting out the expectations of Welsh Government of the NHS to tackle cancer' for the period 2011-16 (Welsh Government, 2012). It is focused on person centred cancer care that is equitable for people of all ages, wherever they live in Wales. The vision is for 'people of all ages to have a minimised risk of developing cancer and, where it does occur, an excellent chance of surviving, wherever they live in Wales', and 'for Wales to be compatible with the best in Europe'. It sets out a focus across a number of outcomes, including prevention, early detection, delivering treatment, meeting people's needs, caring at the end of life, improving information and targeting research. It recognises that: rapid diagnosis and treatment improves survival and quality of life and lessens survivors' longer term care needs; there are inequalities in access to health care in the diagnosis of cancer; people are still being diagnosed with advanced cancer; GPs are crucial in the process of diagnosing cancer timely; that diagnostic testing, particularly Ultrasound and CT must be available to primary care practitioners wherever this will reduce time to diagnosis.

Outcome 2 is 'Cancer is detected quickly where it does occur or recur', and lists ten things it would like to see from NHS cancer care by 2016:

- Easier access to GPs, pharmacists, dentists and opticians
- More information and support services that are easier to access, such as through local pharmacies
- More doctors and nurses available 24 hours a day, 365 days a year
- More direct access to diagnostic tests for the GP
- A greater range of local services meaning less need to travel, particularly for diagnosis and care after treatment
- Reduced travel costs for patients
- Better take up of population screening
- Prompt and appropriate access to assessment and treatment known to work to increase the chance of cure and reduce side effects
- More information on reducing the risk of developing cancer, recognising symptoms suggestive of early cancer and what services to expect available by telephone and on-line
- More men going sooner to their GP or other health services

From this, the Plan mandates actions for Local Health Boards. These are:

- Use of National profiling data of cancer prevalence, mortality and survival rates to inform targeted action on particular cancers and communities
- Raise public awareness of cancer symptoms needing prompt GP assessment
- Raise GP awareness of symptoms to promote prompt referrals in line with national guidance, local pathways and waiting times standards
- Work with GPs to introduce evidence based Risk Assessment Tools to help identify those at most risk of having cancer
- Provide GPs with direct and prompt access to diagnostics to diagnose cancer
- Audit the pathway for each person diagnosed with advanced cancer and act on findings to improve services for early diagnosis
- Develop acute oncology services to support the needs of people admitted as emergencies

Lastly, the Plan also outlines the outcome measures that will be reported annually. These are mostly measurable outcomes (such as mortality, survival), rather than the process measures (such as numbers of doctors, access to diagnostic tests, access to assessment, public awareness, and introduction of Risk Assessment Tools). Hence, in subsequent Annual Reports it is difficult to ascertain progress in early diagnosis made against the aims of the Plan. For example, whilst the most recent report on progress (Welsh Government, 2014) does report some longer term trends of improvements in survival, in relation to early diagnosis it only reports that primary care is undertaking significant event analysis of gastrointestinal and lung cancers, outlines the aims of the newly initiated Macmillan Primary Care Oncology initiative (see Box 1), and highlights free text from the Cancer Patient Experience Survey (indicating areas for improvement including delays around investigation of symptoms in primary care, poor communication and difficult transition phases between primary and secondary care).

#### Box 1. The Macmillan Primary Care Oncology Initiative

This five year primary care oncology programme will support better integrated cancer care across primary, community and secondary care settings and develop clinical leadership. It will facilitate opportunities to support GP education, develop work streams to enhance the first point of contact with symptoms and earlier diagnosis, strengthen co-ordination of care during post treatment and support survivorship phase.

### 3.2. Prudent Healthcare

NHS Wales is taking on the principles of Prudent 'Healthcare' as it responds to the challenges of rising costs and increasing demand, while continuing to improve the quality of care. This was informed by the work of the Bevan Commission (Aylward, 2013) and endeavours to ensure that greater value for patients is achieved.

Prudent healthcare is defined as 'healthcare which is conceived, managed and delivered in a cautious and wise way characterised by forethought, vigilance and care budgeting which activates tangible benefits and quality outcomes for patients' (Aylward, 2013). The objectives of prudent healthcare are that: healthcare fits the needs and circumstances of the citizen; it actively avoids waste and harm; it abandons care that brings little or no benefit; and that it fully exploits the limited financial resource which can be drawn on (Aylward, 2013).

Hence, the general emphasis of prudent healthcare is on changing the culture within the NHS, providing strong leadership, managing efficiency, stopping ineffective and inefficient care and preventing ill health. In delivering this, Public Health Wales has an important role, alongside a shift to give responsibility to the individual to manage their own health by maintaining good health and preventing ill health as far as possible.

In Wales, the cancer budget accounts for £347.1 million and is the fourth biggest spending area (Welsh Government, 2014). The Bevan Commission identified the following priorities:

- Prevention of cancer through smoking cessation and other preventative programmes, including cervical screening
- Early intervention – early diagnosis of cancer to initiate treatment quickly and better outcomes. This includes targeted and selected investigation and referral for patients at a pre-determined level of risk of undiagnosed cancer
- Self-care – shared responsibility for managing health and preventing illness. This includes public awareness of the meaning of symptoms and of appropriate help-seeking.

The recent plan for primary care services in Wales (Welsh Government, 2015) is also based upon the principles of Prudent Healthcare. Whilst it does not address cancer specifically, it reiterates principles underpinning the future direction of primary care (Box 2). However, of relevance to cancer are two of its stated outcomes of measures of a good primary care service. These are 'People are well supported in managing their physical, mental and social health and wellbeing' and 'Timely, safe, effective investigation and diagnosis close to home'. The plan also includes ways of improving access to primary care.

Box 2. Principles underpinning the future direction of primary care in Wales (Welsh Government, 2015)

**Do no harm.** The principle that interventions which do harm or provide no clinical benefit are eliminated.

**Treat the greatest need first.** The principle that people are seen on the basis of clinical priority and according to need.

**Carry out the minimum appropriate intervention.** The principle that treatment should begin with the basic proven tests and interventions. The intensity of testing and treatment is consistent with the seriousness of the illness and the patient's goals.

**Organise the workforce around the 'only do, what only you can do' principle.** The principle that all people working for the NHS in Wales should operate at the top of their clinical competence. Nobody should be seen routinely by a consultant, for example, when their needs could be appropriately dealt with by an advanced nurse practitioner.

**Consistently apply evidence-based medicine in practice.** The principle that all interventions should be proven to be clinically effective. The NHS should not be offering people interventions which have no evidence base of effectiveness.

**Promote equity.** The principle that it is the individual's clinical need which matters when it comes to deciding NHS treatment.

**Remodel the relationship between user and provider on the basis of co-production.** People are treated as equal partners with the professional in agreeing goals, action and care options, including choosing the most prudent course of action.

### 3.3. Comparison with other devolved nations

The impact of Welsh health policy on cancer diagnosis compared with the other devolved nations is unknown. A research study has been commissioned by the Policy division of Cancer Research UK to study this. This study commenced in 2015, and aims to provide Cancer Research UK with recommendations on cancer services and cancer policy to the devolved UK Governments. It should also provide robust evidence about the ways in which cancer diagnostics may be affected by policy.

## **4. International Cancer Benchmarking Partnership – implications for Wales**

### **4.1. Background**

The International Cancer Benchmarking Partnership (ICBP) was set up in 2009 with the aim of generating insight and understanding that will help all partners improve cancer survival outcomes by optimising cancer policies and services. ICBP has 13 member jurisdictions in the UK (England, Wales, Northern Ireland, Scotland), Scandinavia (Denmark, Norway, Sweden), Australia (New South Wales, Victoria), and Canada (Alberta, Manitoba, Ontario, British Columbia). Each member jurisdiction is comparable in terms of: a universal access to health care; wealth; and high-quality, population-based cancer registration system.

Its work has been divided into five modules, each of which is run by a central team, which in turn reports to the international Programme Board. Each jurisdiction had a choice of participating, or not, in each module. Wales has participated (or is still participating) in each of the five modules.

### **4.2. Module 1 - Epidemiology**

Module 1 analysed and compared population-based cancer registry data from 2.4 million adults diagnosed with primary colorectal, lung, breast (women), or ovarian cancer during 1995-2007 in 12 jurisdictions across six countries. The completion of this module has provided an overview of cancer survival in the six different ICBP countries. In summary, survival has improved in the six countries, however survival is significantly lower in the UK, and Wales in particular, when compared to Australia, Canada, Norway and Denmark (Coleman, 2011). Further findings from Module 1 partly explain these differences, highlighting that low survival is associated with more advanced stage at diagnosis in breast (women) (Walters, 2013a), colorectal (Maringe, 2013), lung (Walters, 2013b) and ovarian cancer (Maringe, 2012). Hence access to treatment, staging diagnostics, stage-specific treatments and diagnosis delays are areas for further investigation. Further findings arising from Module 1 offer recommendations to improve the comparability of population-based staging data and hence improve cancer surveillance worldwide (Walters, 2013c).

### **4.3. Module 2 – Population awareness and beliefs about cancer**

As part of Module 2, Wales was involved with the development and testing of an internationally validated measure of awareness and beliefs about cancer (ABC) (Simon, 2012). This measure was administered by telephone interview to 19,079 participants over 50 years old and included questions relevant to symptom awareness, outcome awareness, help-seeking intentions, beliefs about cancer, barriers to symptomatic presentation and age of likely cancer development. Participants in Wales (and the UK in general) had low awareness of age-related risk and the highest perceived barriers to symptomatic presentation, but symptom awareness did not differ from other countries. One of the key barriers to early presentation in the UK was concern about wasting the doctor's time. Therefore, interventions that address barriers to prompt presentation in primary care should be developed and evaluated (Forbes, 2013).

In an ovarian cancer-specific study of the Welsh population, findings suggest that many symptoms of ovarian cancer are not well-recognised. Hence, in order to reduce delays in presentation, evidence-based interventions are needed to improve public awareness and overcome the barriers to recognising and acting on ovarian cancer symptoms (Brain, 2014).

Further research from Module 2 assessed socioeconomic differences in positive and negative attitudes towards cancer in UK adults and concluded that whilst an optimistic perspective exists, there are widespread fears about survival and treatment, especially among less-educated groups. Health education campaigns targeting socioeconomically disadvantaged groups might benefit from a focus on reducing negative attitudes (Quaife, 2015).

#### **4.4. Module 3 – Beliefs, behaviours and systems in primary care**

In this module, which is complete, each jurisdiction aimed to collect detailed questionnaire data from 200 GPs, covering a range of topics relevant to the diagnosis of cancer. This included questions about the practice (size, rurality, appointment length, access), their education and training, GP investigations available to them (and the speed of access and reporting), and access to specialist opinion. Furthermore, the questionnaire then took respondents through a series of hypothetical clinical vignettes that determined the point at which the GP would undertake the diagnostic test that would lead to a cancer diagnosis (Rose, 2014). In summary, across the vignettes, primary care professionals in Wales were generally less likely to act upon symptom presentation and this was found to be associated with decreased survival (Rose, 2015). There are a number of factors that contribute to this including access to tests, waiting times for tests and results, and awareness of test availability. Additionally, results indicated that GPs in Wales feel consistently less able to get access to specialist advice within 48 hours and faster access to tests if needed, when compared to other countries. On most parameters of the factors relating to beliefs, behaviours and systems in primary care pertaining to cancer diagnosis, Wales, compared with the other jurisdiction, performed badly. Hence, this Module provides Wales with very clear findings, indicating how outcomes may be improved.

#### **4.5. Module 4 – Root causes of diagnostic and treatment delays**

In this module each participating jurisdiction aimed to recruit 200 newly diagnosed patients in each of four cancers (breast, colorectal, ovarian and lung) and collect detailed questionnaire data regarding events leading to their diagnosis. This included symptoms, help-seeking behaviour, referrals, investigations, and important dates and timescales for all of these. Furthermore, similar data were sought from their general practices and from the diagnosing secondary care clinicians. Data collection for this module is now largely complete and data analysis is in progress. A protocol paper has been submitted for publication. Initial results are anticipated in summer 2016. The findings will provide a rich and detailed account of the diagnostic processes within and between each of the jurisdictions. These findings are likely to have a direct influence over policy and practice.

#### **4.6. Module 5 – Treatment, co-morbidities and other factors**

Wales will also be participating in ICBP Module 5, with work commencing this year. The core cancer survival benchmarking study highlighted that survival differences might partly be explained by a group of patients who die shortly after diagnosis. To explore this further, two workstreams have been developed for Module 5. The aim of the first is to explore how differences in cancer registry practices and available data sources between countries might affect international comparisons. The Module 5 team have built an online simulation model based on information provided from cancer registry teams in England, Norway, Sweden, Denmark, Canada and Australia. This allows users to adjust a number of key fields,



including date of diagnosis, tumour site and the proportion of patients diagnosed at different stages, and measure any impact on 1-year cancer survival. The second workstream will examine the contribution of co-morbidity to early deaths in lung cancer across the participating international jurisdictions in Europe, Canada and Australia. It will test the hypothesis that patients who die shortly after diagnosis are more likely to be living with one or more co-morbidities. It may be that the presence of co-morbidity affects the likelihood of receiving optimal treatment, and consequently survival. This study is initially focussing on lung cancer and is linking routinely collected data from hospitals, cancer registries and, where available, clinical audits. An international team of collaborators is working on the two workstreams and an independent academic reference group has been appointed to provide peer review on methodology, analyses and conclusions.

#### **4.7. Phase 2 of ICBP**

The second phase of ICBP is in planning. Given the importance and value of the findings to date, and those still forthcoming, it is likely that Wales will continue to benefit hugely from participation in this.

## 5. The evidence regarding timelier diagnosis leading to better outcomes

The crucial question as to whether the cancer outcomes are improved by the timelier (i.e. quicker) diagnosis of symptomatic disease has been the subject of intense research for many decades, and for many different cancers (Neal, 2009). There has been a view, at least for some cancers, that by the time a patient presents with symptoms, the outcome is the same, however quick (or slow) the diagnostic process is from symptom onset, and that quicker diagnosis simply leads to a patient living with the diagnosis for longer (lead time bias). However this is contrary to the biological hypothesis of tumour growth, and the clear wishes of patients to have their cancer diagnosed as quickly as possible after symptoms are noticed.

The body of literature has historically had a number of methodological problems including (Neal 2010):

- Variations in the definitions of time intervals and of outcomes
- Bias in the collection of data relating to time intervals
- Failure to account for the (so-called) 'waiting time paradox' – whereby patients with very aggressive tumours tend to present early with symptoms, get diagnosed early as a result, yet still do poorly as a result of aggressive disease – a form of confounding by indication.

In order to fully explore this, the body of literature was recently brought together in a systematic review which included 209 studies, and 12 previous systematic reviews, across 28 different cancer groupings (Neal, 2015a). The main findings from this were that cancers with more reports of an association between shorter times to diagnosis and more favourable outcomes were breast, colorectal, head and neck, testicular and melanoma. The review concluded that 'we believe it is reasonable to assume that efforts to expedite the diagnosis of symptomatic cancer are likely to have benefits for patients in terms of improved survival, earlier stage diagnosis and improved quality of life, although these benefits vary between cancers'.

Hence, there now appears to be a consensus, supported by systematic review evidence, that there are benefits to clinical outcomes for more timely diagnosis in some cancers. This is clearly accepted within the Welsh Government Cancer Delivery Plan (Welsh Government, 2014). However, both the nature of the benefit (for example stage, survival, patient experience) and the extent of these benefits varies considerably between cancers. Literature in this area continues to increase with the publication of more papers since the end-date of the searches for the recent systematic review; these invariably report positive associations (Murchie, 2014; Brasme, 2014). More high quality studies are needed to explore these issues further. Additionally, the evidence base remains lacking as to the *quality* of life years saved through earlier diagnosis. Lastly, there remain many unanswered questions relating to the cost effectiveness of early diagnosis. One recent report, commissioned by Cancer Research UK, concluded that earlier diagnosis is cost effective, predominantly because early stage treatment is significantly less expensive than that for advanced disease (Incisive Health, 2014). Further, health economic evaluations are needed.

These findings support previous assertions that at least a proportion of the 'lives lost' can potentially be prevented by earlier diagnosis. Furthermore they support (theoretically) the early diagnosis initiatives that have been implemented in England, Scotland, Denmark and elsewhere (see sections 7.2 to 7.4). A recent British Journal of Cancer editorial, reviewing the evidence for earlier diagnosis improving cancer survival concluded: '...that pursuit of earlier diagnosis and optimal treatment can lead to many thousands of patients across the United Kingdom being spared the trauma of a late diagnosis and their life being cut short by

cancer' (Hiom, 2015). For health systems that have yet to formally embark on such activity, the findings add to evidence suggesting that early diagnosis may have an impact on survival.

## 6. How can earlier diagnosis of symptomatic cancer potentially be achieved?

This section will explore the ways in which earlier symptomatic diagnosis may be achieved, based upon current knowledge and from a theoretical perspective. There is clearly no single approach that will have a significant effect on early diagnosis. The multiple factors that contribute to a diagnosis mean that an incremental approach that examines the range of potential interventions and that designs and tests these interventions in different settings is most likely to be effective. There is emerging evidence from the UK and elsewhere that some interventions such as increasing cancer awareness and using risk assessment tools may be beginning to make a difference to cancer diagnostics (Rubin, 2014; Rubin, 2015).

The complexity of the process has been recently highlighted, and a conceptual foundation for the development of future interventions has been proposed to minimise the occurrence of missed opportunities in cancer diagnosis once symptoms have been presented (Lyratzopoulos, 2015a). They consider that missed opportunities may occur in one of three phases: within initial diagnostic assessment; within diagnostic test performance and interpretation; and within diagnostic follow-up and coordination.

One of the first issues to consider is exactly where, timewise, there is most potential to reduce times to diagnosis. An analysis of the relative contribution of the patient and primary care intervals has recently been published which demonstrated the huge variation between cancers (Lyratzopoulos, 2015b). Patient intervals were more than two fold the primary care intervals for ten cancers. The longest median patient intervals in laryngeal, oropharyngeal, cervical, oesophageal, melanoma thyroid, colorectal; most of which present with symptoms that are less typical. The longest median primary care intervals were for myeloma, gall bladder, lung, renal, stomach, and liver. Whilst this was an analysis of English data, it is likely that these findings pertain to a Welsh population also and highlight the reasons for raising awareness of early cancer symptoms/seeking advice.

It is well established that time intervals in diagnosis vary hugely between different cancers (Neal 2014a; Neal & Allgar, 2005; Allgar & Neal, 2005), and that the numbers of pre-referral consultations varies similarly (Lyratzopoulos, 2012). This tells us that, for some cancers, there remain very significant time periods after presentation of symptoms when there may be opportunities to hasten the diagnosis. However, there are patterns to this, and clear reasons why some cancers are harder to diagnose because they are 'harder to suspect' (Lyratzopoulos, 2014). Finding solutions for the harder to suspect and diagnose cancers is more difficult, and this has been highlighted in a number of recent editorials relating to cervical (Walter, 2014), children, teenagers and young adults (Fern, 2013), and educational pieces on how several cancers can be 'easily missed': bladder (Nicholson, 2014), lung (Neal, 2014), pancreatic (Siriwardena, 2014), and myeloma (Hsu, 2012). To improve diagnostic times for this group, there is a need for breakthroughs in diagnostic technology, and more frequent and systematic use of existing tests alongside an understanding of what tests mean and what the limitations are. The authors conclude that 'prolonged diagnostic intervals chiefly reflect limitations in scientific knowledge and in the organisation and delivery of healthcare'. It is also likely that multi-morbidity complicates cancer diagnosis, although there have been few studies regarding this.

Previous work has focused on factors associated with delayed diagnoses. Reviews have shown that for upper gastrointestinal cancer, patient-related research suggests that recognition of symptom seriousness is more important than recognition of the presence of the symptom, and the main factors related to practitioner delay were misdiagnosis, application and interpretation of tests, and the confounding effect of existing disease (Macdonald, 2006). Across cancer sites, non-recognition of symptom seriousness has been identified as the main patient-mediated factor resulting in increased time to presentation

(Macleod, 2009). Furthermore, there is strong evidence of an association between older age and patient delay for breast cancer, lower socio-economic status and delay for upper gastrointestinal and urological cancers and lower education level and delay for breast and colorectal cancers. Barriers to early presentation with lung cancer symptoms include lack of knowledge (Simon, 2012), fatalism and denial (Chatwin, 2014), perceptions that the GP will not be receptive to symptom concerns, and misattribution of symptoms to ageing, smoking habits or comorbid conditions such as COPD (Corner, 2005; Birt, 2014).

### **6.1. Reducing patient intervals by increasing public awareness of symptoms and of appropriate help-seeking behaviour**

It is now well established that in many cancers there are opportunities for earlier diagnosis if patient intervals could be reduced. The evidence for the effectiveness of awareness campaigns has, until recently, been quite limited (Austoker, 2009). A recent review identified forty three studies and concluded that, overall there was some evidence of mass media campaigns having a short term effect on knowledge of symptoms and increased awareness of screening (Campbell, 2014).

Since 2012 there has been a 'Be Clear on Cancer' campaign in England. This has used media advertising to disseminate messages about specific cancer signs and symptoms and appropriate help-seeking behaviour, and initially covered bowel and lung cancers and has since been rolled out to other cancers (Power & Wardle, 2015). The evaluation of the 2012 'Be Clear on Cancer' campaign for lung cancer has recently been published and is the first to suggest a shift in stage distribution following an awareness campaign for lung cancer (Ironmonger, 2014). The authors further suggest that it is possible that the effect of the campaign may lead to a sustained increase in resections which may lead to improved long-term survival. What was clear in this evaluation is that the effect of the evaluation seemed to be seen throughout the health care system, in that there were more GP consultations, and more x-rays and referrals suggesting that the campaign may also have an independent impact on GP behaviour. Furthermore, the 2012 English Be Clear on Cancer campaigns (for lung and bowel cancer) were associated with increased public awareness of some of the key symptoms, but did not reduce barriers to visiting the GP with these symptoms (Power & Wardle, 2015). These two campaigns were found to reach their target audiences and have also influenced younger and more affluent groups, with no widening of equalities (Moffat, 2015).

Community-based interventions that attempt to mobilise social norms and influences have strong potential for engaging hard to reach groups, by promoting positive attitudes towards earlier presentation and minimising fearful/fatalistic beliefs (Chatwin & Saunders, 2013; Whitaker, 2015). The results of other types of interventions, such as a school-based educational intervention to increase adolescent and parent cancer awareness and communication, are awaited (Kyle, 2015).

### **6.2. Reduction of primary care intervals**

Again, there is the potential to act to hasten diagnoses once patients have presented to primary care, although the impact of this is likely to vary from cancer to cancer. Broadly speaking, and informed by the recent framework proposed regarding avoiding missed opportunities (Lyratzopoulos, 2015a) the interventions can be classified into within: initial diagnostic assessment; diagnostic test performance and interpretation; and diagnostic follow-up and coordination.

### *Educational initiatives*

There are a host of interventions that engage and educate GPs and other primary care staff, with the aim of improving diagnoses in the future. These include: educational programmes, currently subject to a Danish trial (Toftegaard, 2014); engagement with significant event audit of cancer diagnosis, which has been reported in England (Mitchell, 2013) and Wales (Neal, 2015b), and currently part of the Welsh Quality and Outcomes Framework. In Denmark, the strategy has been to educate and support GPs as well as change the system (Vedsted & Olesen, 2015).

### *Risk Assessment Tool development and implementation*

Since 2007, a number of different risk assessment tools have been developed with the intention of helping GPs assess the risk of patients having cancer, based upon symptoms, presenting symptoms and other demographic factors. They differ from, for example, cardiovascular risk calculators in that they calculate the risk of actually having currently undiagnosed cancer rather than the risk of developing cancer in the future.

The largest group of these, known as Risk Assessment Tools (RATs), have been developed by Hamilton and have covered: bladder (Shephard, 2012), brain (Hamilton, 2009), breast (Walker, 2014), children (Dommett, 2013a), colorectal (Hamilton, 2009), Hodgkin lymphoma (Shephard, 2015a), kidney (Shephard, 2013), lung (Hamilton, 2009), myeloma (Shephard, 2015b), non-Hodgkin lymphoma (Shephard, 2015c), oesophago-gastric (Stapley, 2013), ovarian (Grewal, 2012), pancreatic (Stapley, 2012), prostate (Hamilton, 2009), teenagers, children and young adults (Dommett, 2013b), and uterine (Walker, 2013). This group have also reported specific studies of some symptoms and signs, including hypercalcaemia (Hamilton, 2014), and jaundice (Taylor, 2012). The studies are based upon data from case control studies using general practice records. They calculate the positive predictive value of specific cancers based upon patients consulting in general practice with specific symptoms (or investigation results), and pairs of these. For some cancers there are age and gender specific values calculated. The tool has been integrated within general practices in England and their use has been promoted as a wider package of GP engagement with cancer (Rubin, 2014). An early evaluation has reported an increase in diagnostic activity and diagnoses associated with their use (Hamilton, 2013). The use of the oesophago-gastric RAT in primary care is currently subject to a cluster randomised controlled trial ([www.dur.ac.uk/school.health/erdu/news/currentprojects/ecdsstudy/](http://www.dur.ac.uk/school.health/erdu/news/currentprojects/ecdsstudy/)).

The second group of these, known as 'QCancer', have been developed by Hippisley-Cox. They are based upon data from prospective derivation and validation cohorts from the QRESEARCH general practice database. In addition to presenting symptoms to general practice, they also take other factors into consideration, including age, gender, BMI, smoking, alcohol, deprivation, anaemia, previous cancer, family history of cancer, and a history of pancreatitis, and types 1 and 2 diabetes. QCancer scores have been published for colorectal, upper gastrointestinal, lung, ovarian, pancreatic and renal cancers, as well as generic 'any cancer' scores for men and women (Hippisley-Cox 2011a, 2011b, 2012a, 2012b, 2012c, 2012d). They are available to use via the QCancer website ([www.qcancer.org/](http://www.qcancer.org/)), and include scores for other cancers other than their published scores. One study has reported difficulty in implementing QCancer scores into Australian general practice because of significant barriers (design and implementation of the tool, variation in the interpretation of clinical histories, therefore variable risk outputs and strong beliefs in personal clinical intuition) (Chiang, 2015).

Lastly, risk tools have been developed by other groups. One of these is for lung cancer (Iyen-Omofoman, 2013), and other is for pancreatic and biliary cancer (Keane, 2014).

Whilst these tools are an advance and appear to be useful, they remain based upon an estimate of risk of cancer. They have the potential to include other factors in the algorithms underpinning them (for example other clinical, risk and socio-demographic information) that may increase the precision of the risk. There are also other mathematical and analytical approaches that may increase precision, for example the use of artificial intelligence (<http://medx.net/>). Lastly the tools do not give the clinician any direction as to how the clinical situation should be managed – for example at what level of risk a patient should be investigated or referred.

Another recent initiative has recently reported preliminary results of using IT in primary care to identify patients who currently fulfil urgent referral criteria for colorectal cancer. This study found that it is technically possible in primary care to do this, but that only 10 out of 809 patients who were ‘flagged’ by the process had a final diagnosis of colorectal cancer (Kidney, 2015).

It is not currently known the extent to which these risk tools are used in Wales.

#### *Lowering thresholds for primary care investigation and referral of patients with potential cancer symptoms*

Several countries have developed guidelines for the primary care management, investigation and referral of patients with potential cancer symptoms. However, these are of varying quality and different processes are used to develop them. Guidelines developed by NICE are regarded as being of high quality, and are adopted for use in England and Wales. NG12 ‘Suspected cancer: recognition and referral’ was published in 2015 (NICE, 2015), updating CG27 (NICE, 2005). This is likely to lead to a major change in clinical practice regarding the primary care management, investigation and referral of patients with potential cancer symptoms. The impact of this on service use, diagnostic times and cancer outcomes is largely unknown at present.

Another approach to reducing primary care intervals is that of lowering the threshold for investigation of patients with potential symptoms of cancer. This is currently being trialled in lung cancer in the ELCID (Early Lung Cancer Diagnosis and Investigation) trial (Hurt, 2013). This trial is evaluating the effect of offering urgent chest X-Rays to higher risk patients (smokers or ex-smokers aged 60+) who present with a new chest symptom.

#### *Widening and hastening access to investigations and specialist opinion*

Other initiatives that have the potential to reduce the primary care interval include: *hastening* and *widening* access to imaging and other diagnostic investigations, and to specialist opinion. This has been successfully implemented in Denmark (Vedsted & Olesen, 2015), and is being undertaken in locations in England as part of the ACE programme (Accelerate Coordinate and Evaluate). Evidence is beginning to emerge regarding better stage outcomes being associated with higher rates of investigation, especially for upper GI endoscopy (Shawihdi, 2014).

### **6.3. Hastening diagnosis through system change**

Once patients have a suspicion of cancer on an investigation or have been referred for specialist opinion, there is the potential for interventions to ensure that the diagnosis is made as rapidly as possible. These include: seamless sequencing of subsequent investigations

and clinic appointments; preventing patients ‘bouncing’ between departments; excellent communication with patients and all clinicians involved in the process; and timely instigation of treatment.

Lastly, it is well established that cancer diagnoses made after an emergency admission have poorer outcomes and hence a high rate of emergency diagnoses are a ‘marker’ for poorer outcomes. Hence, interventions aimed at preventing emergency diagnoses have the potential to improve outcomes. However, recent work has demonstrated that presentation through an emergency route may be associated with both psychological processes which can delay seeking medical help and with difficulties in suspecting the diagnosis of cancer after presentation (Abel, 2015). Other recent work has demonstrated that there is subsequent primary care input into cases diagnosed through emergency presentations, and the complexity of the presentation and patient factors (Mitchell, 2015). Hence, whilst there may be opportunities for the diagnosis to be made earlier, in practice it may be difficult to do so, and useful interventions in this area may be difficult to design and evaluate as it may be the cumulative effect of interventions that makes a difference.

#### **6.4. Reducing socioeconomic, age and gender inequalities**

Inequalities exist throughout cancer screening, diagnosis, treatment, and therefore survival, whether by socio-economic disadvantage, age, ethnic group or gender. For example, recent analyses have demonstrated:

- The potential to substantially reduce deaths within five years of a melanoma diagnosis by reducing socioeconomic and sex inequalities – by designing and evaluating interventions to reduce patient intervals (Rutherford, 2015a)
- The potential to reduce deaths from breast cancer by eliminating age inequalities – by targeted campaigns aimed at encouraging prompt presentation (Rutherford, 2015b)
- Age and gender-specific inequalities in the timeliness of diagnosis for some but not all cancer types (Din, 2015)
- Gender inequalities in the promptness of bladder and renal cancer diagnosis (Lyrtzopoulos, 2013).



## 7. What activities are currently happening in Wales and other similar countries to achieve earlier diagnosis?

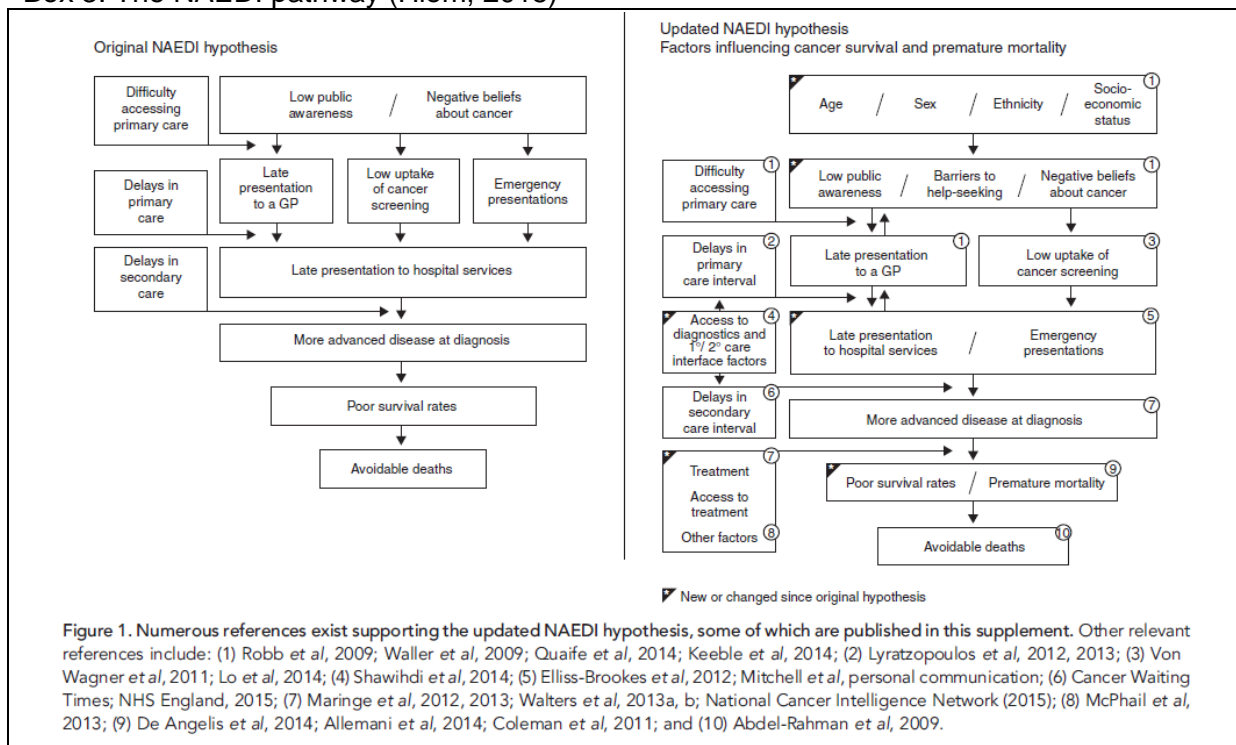
### 7.1. Current activity in Wales

The structure of NHS Wales means that there both local (run by Health Boards in support of the Cancer Delivery Plan) and all-Wales activity, through Welsh Government, and in turn through Public Health Wales. All-Wales activity relating to improving cancer diagnosis is coordinated through the Cancer National Specialist Advisory Group Core Team and the Cancer Implementation Group (CIG). One focus of current activity is the Lung Cancer Initiative - this is developing work to raise awareness of cancer symptoms and help-seeking behaviour, work targeted at expediting lung cancer diagnosis through primary care (including analysis of significant event audits from primary care), and work to improve data capture regarding outcomes. Another area of activity is a WCISU Project Board that is examining a number of issues relating to primary care diagnostics, including: reporting cancer outcomes by GP cluster; routes into diagnosis; and examining routine primary care data.

### 7.2. National Awareness and Early Diagnosis Initiative

Following the publication of the Cancer Reform Strategy (Department of Health, 2007), the English National Awareness and Early Diagnosis Initiative (NAEDI) was set up in 2008 with the aim of understanding and addressing the reasons for late diagnosis of cancer in England (Richards 2009b). This has focused on low awareness of cancer symptoms, delays in primary care, and delays post-referral from primary care. Its work encompasses a number of domains including awareness raising, supporting primary care, a primary care audit of diagnoses, system change and innovations and an evaluative and research funding programme. The original 'NAEDI pathway' has now been updated (Box 3).

Box 3. The NAEDI pathway (Hiom, 2015)



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The NAEDI work relating to primary care has recently been summarised and assessed (Rubin, 2015). This concluded that specific primary care initiatives (such as participation in quality improvement activities including clinical audit, significant event analysis, use of risk assessment tools, and development of practice plans) promoted by cancer networks, had 'and additional and positive impact on urgent referrals for suspected cancer'. Most of this NAEDI work that has taken place in England could be easily replicated in Wales

More recent NAEDI activity, through the Department of Health, has focused on the ACE programme. This is aiming to build on service and pathway development activity in England with the aim of improving early diagnosis and, through robust evaluation, inform the commissioning intentions of the future. Initial ACE pilots have been commissioned and will be evaluated.

### 7.3. Detect Cancer Early – Scotland

The 'Detect Cancer Early' campaign in Scotland was launched February 2012 with £30m funding (<http://www.gov.scot/Topics/Health/Services/Cancer/Detect-Cancer-Early>). The rationale behind the initiative was that Scotland was lagging behind European average five year survival rates, and one of the reasons for this was late diagnosis. It aimed to increase early detection of cancer by 25% by end of 2015, with the objectives of:

- Increasing % of people with stage 1 disease at diagnosis
- Improving participation in screening programmes
- Raising awareness of screening programmes
- Raising awareness of early signs and symptoms and seeking help earlier
- Working with GPs to promote earliest referral/investigation
- Ensuring sufficient capacity in screening, diagnostic and treatment services to meet increase in demand
- To strengthen data collection and performance reporting
- To facilitate further evaluation of the impact of public awareness campaigns

Detect Cancer Early began with a generic 'primer' social marketing campaign using a range of media (TV, radio, digital media, posters, PR and field events), which ran for six weeks in early 2012. The key message was 'Don't get scared, get checked'. The results of this primer campaign were:

- High rate of coverage achieved (98% of target audience, average of 15 times viewed/heard)
- 25,000 people engaged with on field events (road shows)
- Recruited over 4,000 partners (faith groups, local shops and newsagents) to spread campaign message – almost double the target
- Spontaneous awareness of 'getting checked early' increased from 57% - 64%
- People claiming to self-examine increased from 65% to 70%
- 18% of those who'd seen TV advertisement recalled specific aspects – this is significantly more than England's Be Clear on Cancer
- Just under half felt more confident about approaching GP as result of seeing campaign

However, less successful aspects of the campaign were: the over 75s not engaging so well; men engaging less than women; and whilst the 'get checked' message was highly successful, the 'don't get scared' or 'don't worry about feeling silly about approaching your GP' were less so.

Subsequent to this three tumour specific campaigns have been conducted. Breast was launched in September 2012 and ran for two months, colorectal in February 2013 and ran for six weeks, and lung was launched in November 2013.

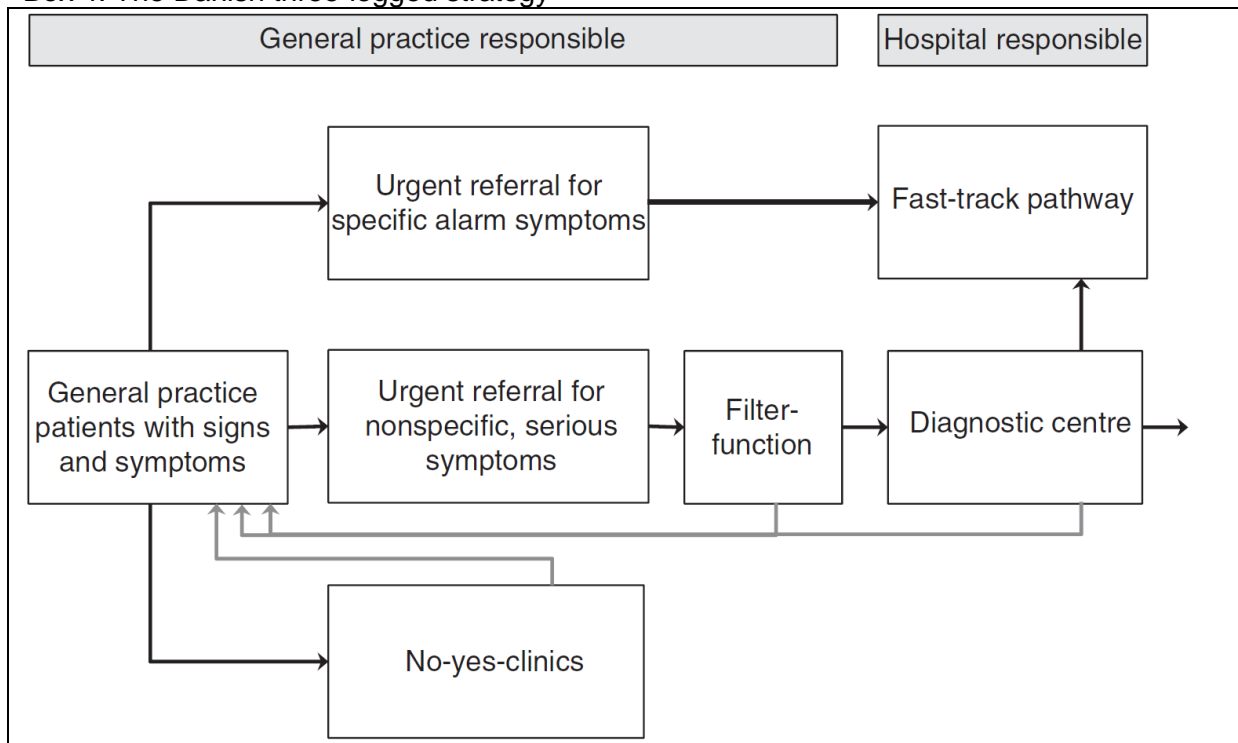
## 7.4. Denmark

Faced with poor cancer outcomes and a problem with late diagnosis (Olesen, 2009), there have been a number of initiatives to improve cancer diagnosis in Denmark. Having initially adopted a two-week referral scheme (similar to the UK), this has developed much further into the Danish three-legged strategy (Vedsted & Olesen, 2015). This is based on the premise that early stage cancer presents very differently in general practice and a focus on alarm or red flag symptoms (as are prioritised by urgent referrals) may not be sufficient. This strategy includes:

- Urgent referral pathways for symptoms suspicious of a specific cancer
- Urgent referral to diagnostic centres when quick and profound evaluation of patients with non-specific serious symptom
- East and fast access to 'no/yes clinics' for cancer investigations for those patients with common symptoms in those whom the diagnosis of cancer should not be missed.

The structure of this is shown in Box 4. The strategy is backed by research, evaluation and education. As with England the changes initiated within Denmark could be replicated within Wales.

Box 4. The Danish three-legged strategy



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## 8. Recommendations for future initiatives to expedite cancer diagnosis in Wales

The main purpose of this report is to set the agenda for cancer priorities through a number of recommendations for implementation and research. In this section these recommendations will be outlined. These are generic for cancer type, unless otherwise specified.

### 8.1. Recommendations for implementation

There are a number of actions that can be implemented now, without need for further research evaluation, which would be likely to have a beneficial effect on outcomes, through earlier symptomatic diagnosis. All of these recommendations have cost and resource implications that will need addressing, especially within the era of Prudent Healthcare. Some of the recommendations are deliberately very generic. Some of these recommendations reflect actions that are at least partly in progress already. Recommendations are listed by target organisation for action.

#### Recommendations for Welsh Government

**Recommendation 1:** To make the early diagnosis of cancer a governmental priority. One way of doing this would be to support the development and activity of a Welsh Awareness and Early Diagnosis Initiative (WAEDI), or similar. This would need to be based upon the successful elements of NAEDI (England) and Diagnose Cancer Early (Scotland). Welsh Government, Public Health Wales, Health Boards and the Third Sector (principally cancer charities) would need to work together to establish the political will and resource to establish this. Such an initiative could form the framework for a strategy to address all of the recommendations below.

Timescale – over next 12 months.

**Recommendation 2:** To consider adopting a similar approach in Wales to that developed in Denmark for the assessment of patients with symptoms. This will be dependent upon successful research evaluations of their strategy, which are awaited, and new NICE guidelines. A thorough research and evaluation programme would be needed to support this.

Timescale – over next 24 months.

**Recommendation 3:** To support ongoing and future initiatives aimed at increasing cancer awareness, for all cancer types in Wales. These need to be developed for different cancer types and target groups, and need comprehensive evaluation as to their impact. These initiatives will need to be undertaken in collaboration with Public Health Wales and Health Boards.

Timescale – over next 36 months.

**Recommendation 4:** To support the participation of Wales in modules of Phase 2 of the International Cancer Benchmarking Partnership

Timescale – over next 12 months.

#### Recommendations for Health Boards

**Recommendation 5:** To support ongoing and future initiatives aimed at increasing cancer awareness, for all cancer types in Wales. These need to be developed for different cancer types and target groups, and need comprehensive evaluation as to their impact (because at

present good longer term evaluation is missing). These initiatives will need to be undertaken in collaboration with Welsh Government and Public Health Wales.

Timescale – over next 36 months.

**Recommendation 6:** To fully engage primary care staff with issues regarding cancer diagnosis through primary care, and provide resource for timely diagnosis. This work needs to be undertaken with Public Health Wales and in collaboration with the Third Sector (e.g. Macmillan Cancer Support and Tenovus Cancer Care). Activity needs to embrace educational approaches, ongoing monitoring and learning from significant event audits, cluster working, and re-designing pathways to diagnosis. Health Boards also need to work towards providing primary care with sufficient resource for patients to be able to access clinicians in a timely manner and to have sufficient time within consultations to properly address potential cancer signs, symptoms and concerns of cancer. Lastly, it is the responsibility of Health Boards, working with primary care to implement the new NICE guideline on the investigation and referral of patients with cancer symptoms.

Timescale – over next 12 months.

**Recommendation 7:** To provide wider and faster access for diagnostic investigations and specialist opinion from primary care. Wider access needs to embrace pathways for imaging, and laboratory investigation. Faster access to investigation and prompt reporting of results needs investment and system change, to manage increased number of tests and consequences of the results.

Timescale – over next 24 months.

**Recommendation 8:** To streamline diagnostic pathways for all patients with potential symptoms of cancer (whether 'Urgent Suspected Cancer' or otherwise). This needs to cover the sequencing of investigations with clinic visits and further investigations, whilst keeping an informed patients and GPs at the centre of the process.

Timescale – over next 24 months.

### Multi-agency Recommendations

**Recommendation 9:** To support ongoing and future initiatives aimed at increasing cancer awareness, for all cancer types in Wales. These need to be developed for different cancer types and target groups, and need comprehensive evaluation as to their impact (encompassing analysis of routine data, empirical data collection, and process measures). These initiatives will need to be undertaken in collaboration with Welsh Government and Health Boards.

Timescale – over next 36 months.

**Recommendation 10:** To develop routine linkage of GP data via Audit+ to the WCISU cancer registry. This would enable, for example, the measurement of intervals in cancer diagnosis and diagnostic routes, and development of patient-level measures of co-morbidity of cancer patients. It would also allow ongoing monitoring and analysis over time.

Timescale – over next 12 months.

## 8.2. Research Recommendations

A number of specific recommendations pertaining to improving early diagnosis of symptomatic cancer in Wales. These are made within the context of the draft Public Health Wales Research Strategy 2015-18. For these recommendations to be carried out, close collaboration will be needed with the Public Health Wales Research & Development Office, and with three of the recently funded Health and Care Research Wales (formerly NISCHR)

Centres (National Centre for Population Health and Wellbeing, PRIME Centre Wales – the Wales Centre for Primary and Emergency Care Research, and the Wales Cancer Research Centre). Where possible, collaboration with the Secure Anonymised Information Linkage (SAIL) should be undertaken. No specific timescales are included for these as timescales in research are driven by funding decisions, and the general recommendation is for proposals to be developed and funding sought as soon as is practicable.

**Research recommendation 1:** To seek further funding for proposals regarding the public awareness of cancer symptoms in Wales. This should focus on developing and evaluating interventions to engage high risk 'harder to reach' populations in symptom awareness and earlier presentation, and in particular, rigorous evaluation of the proposed lung cancer awareness campaign, including medium and longer term outcomes across the whole NAEDI pathway.

**Research recommendation 2:** To seek further funding for proposals to expedite and maximise the efficiency of cancer diagnosis through primary care in Wales. In particular this should include proposals which: gain a full understanding of the primary care diagnosis of all cancer types (this could be achieved through an ongoing national audit of cancer diagnosis in Wales); evaluate the impact of educational interventions in primary care; evaluate the impact of interventions designed to avoid missed opportunities in the diagnostic pathway; and develop and test newer diagnostic tools.

**Research recommendation 3:** To seek funding for proposals aimed specifically at the 'harder to diagnose' cancers and those cancer types with a higher incidence and poorer outcomes in Wales (for example, lung, brain, myeloma, upper gastro-intestinal). In particular, these should focus on gathering all the data needed to understand the diagnosis of these cancers and then to develop interventions to evaluate (hence systematic reviews, qualitative studies, analysis of existing data, and trial development).

**Research recommendation 4:** To seek funding for a proposal that aims to fully evaluate the health economics of earlier cancer diagnosis in Wales.

## 9. References

- Abel GA, Shelton J, Johnson S, Elliss-Brookes L, Lyratzopoulos G. Cancer-specific variation in emergency presentation by sex, age and deprivation across 27 common and rarer cancers. *British Journal of Cancer*, 2015;**112**:S129-S136.
- Allgar VL, Neal RD. Delays in the diagnosis of six cancers: analysis of data from the 'National Survey of NHS Patients: Cancer'. *British Journal of Cancer*, 2005;**92**:1959-1970.
- Austoker J, Bankhead C, Forbes LJL, Atkins L, Martin F, Robb K, Wardle J, Ramirez AJ. Interventions to promote cancer awareness and early presentation: systematic review. *British Journal of Cancer*, 2009;**101**:S31-S39.
- Aylward M, Phillips C, Howson H, The Bevan Commission. Simply Prudent Healthcare, achieving better care and value for money in Wales - discussion paper. Welsh Government, Cardiff: 2013.
- Birt L, Hall N, Emery J, Banks J, Mills K, Johnson M, Hamilton W, Walter FM. Responding to symptoms suggestive of lung cancer: a qualitative interview study. *BMJ Open* 2014;**1**:e000067.
- Brain KE, Smits S, Simon AE, Forbes LJ, Roberts C, Robbe IJ, Steward J, White C, Neal RD, Hanson J, ICBP Module 2 Working Group. Ovarian cancer symptom awareness and anticipated delayed presentation in a population sample. *BMC Cancer*, 2014;**14**:171.
- Brasme J, Chalumeau M, Oberlin O, Valteau-Couanet D, Gaspar N. Time to Diagnosis of Ewing Tumors in Children and Adolescents Is Not Associated With Metastasis or Survival: A Prospective Multicenter Study of 436 Patients. *Journal of Clinical Oncology*, 2014;**32**:1935-1940.
- Campbell C, Hammersley V, Weller D (on behalf of the ABC-DEEP consortium). Evaluations of awareness campaigns. University of Edinburgh, 2014.
- Chatwin J, Povey A, Kennedy A, Frank T, Firth A, Booton R, Barber P, Saunders C. The mediation of social influences on smoking cessation and awareness of the early signs of lung cancer. *BMC Public Health* 2014;**14**:1043-1054.
- Chatwin J, Saunders C. The influence of social factors on help-seeking for people with lung cancer. *Eur J Cancer Care* 2013;**22**:709-713.
- Chiang PP, Glance D, Walker J, Walter FM, Emery JD. Implementing a QCancer risk tool into general practice consultations: an exploratory study using simulated consultations with Australian general practitioners. *British Journal of Cancer*, 2015;**112**:S77-S83.
- Coleman MP, Forman D, Bryant H, Butler J, Rachet B, Maringe C, Nur U, Tracey E, Coory M, Hatcher J, McGahan CE, Turner D, Marrett L, Gjerstorff ML, Johannesen TB, Adolfsson J, Lambe M, Lawrence G, Meechan D, Morris EJ, Middleton R, Steward J, Richards MA, ICBP Module 1 Working Group. Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995-2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data. *Lancet*, 2011;**377**:127-138.
- Corner J, Hopkinson J, Fitzsimmons D, Barclay S, Muers M. Is late diagnosis of lung cancer inevitable? Interview study of patients' recollections of symptoms before diagnosis. *Thorax* 2005;**60**:314-319.
- Department of Health. Cancer Reform Strategy. Department of Health, London: 2007.
- Din NU, Ukoumunne OC, Rubin G, Hamilton W, Carter B, Stapley S, Neal RD. Age and gender inequalities in cancer diagnostic intervals in 15 cancers: primary care routinely collected data analysis from the UK General Practice Research Database. *PlosOne* 2015 **10**(5): e0127717.

Dommett RM, Redaniel T, Stevens MC, Martin RM, Hamilton W. Risk of childhood cancer with symptoms in primary care: a population-based case-control study. *British Journal of General Practice*, 2013a;**63**:e22-e29.

Dommett RM, Redaniel MT, Stevens MCG, Hamilton W, Martin RM. Features of cancer in teenagers and young adults in primary care: a population-based nested case-control study. *British Journal of Cancer*, 2013b;**108**:2329-2333.

Ferlay J, Steliarova-Foucher E, Lortet-Tieulent J, Rosso S, Coebergh JWW, Comber H, Forman D, Bray F. Cancer incidence and mortality patterns in Europe: estimates for 40 countries in 2012. *European Journal of Cancer*, 2013;**49**:1374-1403.

Fern LA, Birch R, Whelan J, Cooke M, Sutton S, Neal RD, Gerrand C, Hubbard G, Smith S, Lethaby C, Dommett R, Gibson F. Why can't we improve the timeliness of cancer diagnosis in children, teenagers, and young adults? *BMJ*, 2013;**347**:f6493.

Forbes LJ, Simon AE, Warburton F, Boniface D, Brain KE, Dessaix A, Donnelly C, Haynes K, Hvidberg L, Lagerlund M, Lockwood G, Tishelman C, Vedsted P, Vigmostad MN, Ramirez AJ, Wardle J, International Cancer Benchmarking Partnership Module 2 Working Group. Differences in cancer awareness and beliefs between Australia, Canada, Denmark, Norway, Sweden and the UK (the International Cancer Benchmarking Partnership): do they contribute to differences in cancer survival? *British Journal of Cancer*, 2013;**108**:292-300.

Grewal K, Hamilton W, Sharp D. Ovarian cancer prediction: development of a scoring system for primary care. *British Journal of Obstetrics & Gynaecology*, 2013;**120**:1016-1019.

Hamilton W. The CAPER studies: five case-control studies aimed at identifying and quantifying the risk of cancer in symptomatic primary care patients. *British Journal of Cancer*, 2009;**101**:S80-86.

Hamilton W, Green T, Martins T, Elliott K, Rubin G, Macleod U. Evaluation of risk assessment tools for suspected cancer in general practice: a cohort study. *British Journal of General Practice*, 2013;**63**:e30-6.

Hamilton F, Carroll R, Hamilton W, Salisbury C. The risk of cancer in primary care patients with hypercalcaemia: a cohort study using electronic records. *British Journal of Cancer*, 2014;**111**:1410-1412.

Hiom SC. Diagnosing cancer earlier: reviewing the evidence for improving cancer survival. *British Journal of Cancer*, 2015;**112**:S1-S5.

Hippisley-Cox J, Coupland C. Identifying patients with suspected gastro-oesophageal cancer in primary care: derivation and validation of an algorithm. *British Journal of General Practice*, 2011a;**61**:e707-e714.

Hippisley-Cox J, Coupland C. Identifying patients with suspected lung cancer in primary care: derivation and validation of an algorithm. *British Journal of General Practice*, 2011b;**61**:e715-e723.

Hippisley-Cox J, Coupland C. Identifying patients with suspected colorectal cancer in primary care: derivation and validation of an algorithm. *British Journal of General Practice*, 2012a;**62**:e29-e37.

Hippisley-Cox J, Coupland C. Identifying women with suspected ovarian cancer in primary care: derivation and validation of algorithm. *BMJ*, 2012b;**344**:d8009.

Hippisley-Cox J, Coupland C. Identifying patients with suspected pancreatic cancer in primary care: derivation and validation of an algorithm. *British Journal of General Practice*, 2012c;**62**:e38-e45.

Hippisley-Cox J, Coupland C. Identifying patients with suspected renal tract cancer in primary care: derivation and validation of an algorithm. *British Journal of General Practice*, 2012d;**62**:e251-e260.



House of Commons Library. Cancer Statistics: In Brief. SN06877, 2014

Hsu DC, Wilkenfeld P, Joshua DE. Easily missed? Multiple myeloma. *BMJ*, 2012;**344**:d7953.

Hurt C, Roberts K, Rogers T, Griffiths G, Hood K, Prout H, Nelson A, Fitzgibbon J, Barham A, Thomas-Jones E, Edwards R, Yeo S, Hamilton W, Tod A, Neal R. A feasibility study examining the effect on lung cancer diagnosis of offering a chest X-ray to higher-risk patients with chest symptoms: protocol for a randomized controlled trial. *Trials*, 2013;**14**:405.

Incisive Health. Saving lives, averting costs. An analysis of the financial implications of achieving earlier diagnosis of colorectal, lung and ovarian cancer. A report prepared for Cancer Research UK. 2014.

Ironmonger L, Ohuma E, Ormiston-Smith N, Gildea C, Thomson CS, Peake MD. An evaluation of the impact of large-scale interventions to raise public awareness of a lung cancer symptom. *British Journal of Cancer*, 2015;**112**:207-216.

Iyen-Omofoman B, Tata LJ, Baldwin DR, Smith CJ, Hubbard RB. Using socio-demographic and early clinical features in general practice to identify people with lung cancer earlier. *Thorax*, 2013;**68**:451-459.

Keane MG, Horsfall L, Rait G, Pereira SP. A case-control study comparing the incidence of early symptoms in pancreatic and biliary tract cancer. *BMJ Open*, 2014;**4**:e005720.

Kidney E, Berkman L, Macherianakis A, Morton D, Dowswell G, Hamilton W, Ryan R, Awbery H, Greenfield S, Marshall T. Preliminary results of a feasibility study of the use of information technology for identification of suspected colorectal cancer in primary care: the CREDIBLE study. *British Journal of Cancer*, 2015;**112**:S70-S76.

Kyle RG, Macmillan I, Rauchhaus P, O'Carroll R, Neal RD, Forbat L, Haw S, Hubbard G. Adolescent Cancer Education (ACE) to increase adolescent and parent cancer awareness and communication: study protocol for a cluster randomised controlled trial. *Trials*, 2013;**14**:286-286.

Lyratzopoulos G, Neal RD, Barbiere JM, Rubin GP, Abel GA. Variation in number of general practitioner consultations before hospital referral for cancer: findings from the 2010 National Cancer Patient Experience Survey in England. *Lancet Oncology*, 2012;**13**:353-365.

Lyratzopoulos G, Abel GA, McPhail S, Neal RD, Rubin GP. Gender inequalities in the promptness of diagnosis of bladder and renal cancer after symptomatic presentation: evidence from secondary analysis of an English primary care audit survey. *BMJ Open*, 2013;**3**:e002861.

Lyratzopoulos G, Wardle J, Rubin G. Rethinking diagnostic delay in cancer: how difficult is the diagnosis? *BMJ*, 2014;**349**:g7400

Lyratzopoulos G, Vedsted P, Singh H. Understanding missed opportunities for more timely diagnosis of cancer in symptomatic patients after presentation. *British Journal of Cancer*, 2015a;**112**:S84-S91.

Lyratzopoulos G, Saunders CL, Abel GA, McPhail S, Neal RD, Wardle J, Rubin GP. The relative length of the patient and the primary care interval in patients with 28 common and rarer cancers. *British Journal of Cancer*, 2015b;**112**:S35-S40.

Macdonald S, Macleod U, Campbell NC, Weller D, Mitchell E. Systematic review of factors influencing patient and practitioner delay in diagnosis of upper gastrointestinal cancer. *British Journal of Cancer*, 2006;**94**:1272-1280.

Macleod U, Mitchell ED, Burgess C, Macdonald S, Ramirez AJ. Risk factors for delayed presentation and referral of symptomatic cancer: evidence for common cancers. *British Journal of Cancer*, 2009;**101**:S92-S101.

Maringe C, Walters S, Butler J, Coleman MP, Hacker N, Hanna L, Mosgaard BJ, Nordin A, Rosen B, Engholm G, Gjerstorff ML, Hatcher J, Johannesen TB, McGahan CE, Meechan D, Middleton R, Tracey E, Turner D, Richards MA, Rachet B. Stage at diagnosis and ovarian cancer survival: Evidence from the International Cancer Benchmarking Partnership. *Gynecologic Oncology*, 2012;**127**:75-82.

Maringe C, Walters S, Rachet B, Butler J, Fields T, Finan P, Maxwell R, Nedrebo B, Pahlman L, Sjøvall A, Spigelman A, Engholm G, Gavin A, Gjerstorff ML, Hatcher J, Johannesen TB, Morris E, McGahan CE, Tracey E, Turner D, Richards MA, Coleman MP, ICBP Module 1 Working Group. Stage at diagnosis and colorectal cancer survival in six high-income countries: a population-based study of patients diagnosed during 2000-2007. *Acta Oncologica*, 2013;**52**:919-932.

Mitchell ED, Rubin G, Macleod U. Understanding diagnosis of lung cancer in primary care: qualitative synthesis of significant event audit reports. *British Journal of General Practice*, 2013;**63**:e37-e46.

Mitchell ED, Rubin G, Merriman L, Macleod U. The role of primary care in cancer diagnosis via emergency presentation: qualitative synthesis of significant event reports. *British Journal of Cancer*, 2015;**112**:S50-S56.

Moffat J, Bentley A, Ironmonger L, Boughey A, Radford G, Duffy S. The impact of national cancer awareness campaigns for bowel and lung cancer symptoms on sociodemographic inequalities in immediate key symptom awareness and GP attendances. *British Journal of Cancer*, 2015;**112**:S14-S21.

Murchie P, Raja EA, Brewster DH, Campbell NC, Ritchie LD, Robertson R, Samuel L, Gray N, Lee AJ. Time from first presentation in primary care to treatment of symptomatic colorectal cancer: effect on disease stage and survival. *British Journal of Cancer*, 2014;**111**:461-469.

Neal RD, Allgar VL. Sociodemographic factors and delays in the diagnosis of six cancers: analysis of data from the 'National Survey of NHS Patients: Cancer'. *British Journal of Cancer*, 2005;**92**:1971-1975.

Neal RD. Do diagnostic delays in cancer matter? *British Journal of Cancer*, 2009;**101**:S9-S12.

Neal RD, Din NU, Hamilton W, Ukoumunne OC, Carter B, Stapley S, Rubin G. Comparison of cancer diagnostic intervals before and after implementation of NICE guidelines: analysis of data from the UK General Practice Research Database. *British Journal of Cancer*, 2014a;**110**:584-592.

Neal RD, Hamilton W, Rogers TK. Easily missed? Lung cancer. *BMJ*, 2014b;**349**:g6560.

Neal RD, Tharmanathan P, France B, Din NU, Cotton S, Fallon-Ferguson J, Hamilton W, Hendry A, Hendry M, Lewis R, Macleod U, Mitchell ED, Pickett M, Rai T, Shaw K, Stuart N, Torring ML, Wilkinson C, Williams B, Williams N, Emery J. Is increased time to diagnosis and treatment in symptomatic cancer associated with poorer outcomes? Systematic review. *British Journal of Cancer*, 2015a;**112**:S92-S107.

Neal RD, Robbé IJ, Lewis M, Williamson I, Hanson J. The complexity and difficulty of diagnosing lung cancer: findings from a national primary-care study in Wales. *Primary Health Care Research & Development* 2015b;**16**(5):436-449.

NICE. Ovarian cancer: The recognition and initial management of ovarian cancer. Clinical Guideline 122. NICE, 2011

NICE. Referral guidelines for suspected cancer. Clinical Guideline 27. NICE, 2005

Nicholson BD, McGrath JS, Hamilton W. Easily missed? Bladder cancer in women. *BMJ*, 2014;**348**:g2171

Olesen F, Hansen RP, Vedsted P. Delay in diagnosis: the experience in Denmark. *British Journal of Cancer*, 2009;**101**:S5-S8.

Power E, Wardle J. Change in public awareness of symptoms and perceived barriers to seeing a doctor following Be Clear on Cancer campaigns in England. *British Journal of Cancer*, 2015;**112**:S22-S26.

Public Health Wales. A healthier, happier and fairer Wales. Public Health Strategy. 2014

Quaife SL, Winstanley K, Robb KA, Simon AE, Ramirez AJ, Forbes LJ, Brain KE, Gavin A, Wardle J. Socioeconomic inequalities in attitudes towards cancer: an international cancer benchmarking partnership study. *European Journal of Cancer Prevention*, 2015;**24**:253-260.

Richards MA. The size of the prize for earlier diagnosis of cancer. *British Journal of Cancer* 2009a;**101**:S125-129.

Richards MA. The National Awareness and Early Diagnosis Initiative in England: assembling the evidence. *British Journal of Cancer* 2009b;**101**:S1-4.

Rose PW, Hamilton W, Aldersey K, Barisic A, Dawes M, Foot C, Grunfeld E, Hart N, Neal RD, Pirotta M, Sisler J, Thulesius H, Vedsted P, Young J, Rubin G, ICBP Module 3 Working Group\*. Development of a survey instrument to investigate the primary care factors related to differences in cancer diagnosis between international jurisdictions. *BMC Family Practice*, 2014;**15**:122.

Rose PW, Rubin G, Perera-Salazar R, Saur Almborg S, Barisic A, Dawes M, Grunfeld E, Hart N, Neal RD, Pirotta M, Sisler J, Konrad K, Skjødberg Toftegaard B, Thulesius H, Vedsted P, Young J, Hamilton W, The ICBP Module 3 Working Group. Explaining variation in cancer survival between eleven jurisdictions in the International Cancer Benchmarking Partnership: a primary care vignette survey. *BMJ Open*, 2015;**5**:e007212.

Rubin G, Walter F, Emery J, Neal R, Hamilton W, Wardle J. Research into practice: prompt diagnosis of cancer in primary care. *British Journal of General Practice*, 2014;**64**:428-430.

Rubin G, Gildea C, Wild S, Shelton J, Ablett-Spence I. Assessing the impact of an English national initiative for early cancer diagnosis in primary care. *British Journal of Cancer*. 2015;**112**:S57-64.

Rutherford MJ, Ironmonger L, Ormiston-Smith N, Abel GA, Greenberg DC, Lyratzopoulos G, Lambert PC. Estimating the potential survival gains by eliminating socioeconomic and sex inequalities in stage at diagnosis of melanoma. *British Journal of Cancer*, 2015a;**112**:S116-S123.

Rutherford MJ, Abel GA, Greenberg DC, Lambert PC, Lyratzopoulos G. The impact of eliminating age inequalities in stage at diagnosis on breast cancer survival for older women. *British Journal of Cancer*, 2015b;**112**:S124-S128.

Shawihdi M, Thompson E, Kapoor N, Powell G, Sturgess, RP, Stern N, Roughton M, Pearson MG, Bodger K. Variation in gastroscopy rate in English general practice and outcome for oesophagogastric cancer: retrospective analysis of Hospital Episode Statistics. *Gut* 2014;**63**:250-261.

Shephard EA, Stapley S, Neal RD, Rose P, Walter FM, Hamilton WT. Clinical features of bladder cancer in primary care. *British Journal of General Practice*, 2012;**62**:e598-e604.

Shephard E, Neal RD, Rose P, Walter F, Hamilton WT. Clinical features of kidney cancer in primary care: a case-control study using primary care records. *British Journal of General Practice*, 2013;**63**:e250-e255.

Shephard EA, Neal RD, Rose P, Walter F, Hamilton W. Quantifying the risk of Hodgkin lymphoma in symptomatic primary care patients: a case-control study using electronic records. *British Journal of General Practice*, 2015a;**65**:e281-287.

Shephard EA, Neal RD, Rose P, Walter FM, Litt EJ, Hamilton WT. Quantifying the risk of multiple myeloma from symptoms reported in primary care patients: a large case-control study using electronic records. *British Journal of General Practice*, 2015b;**65**:e106-e113.

Shephard EA, Neal RD, Rose P, Walter F, Hamilton W. Quantifying the risk of Non-Hodgkin lymphoma from symptoms reported by primary care patients: a large case-control study using electronic records. *British Journal of General Practice* 2015c;**65**:e281-287.

Simon AE, Juszczak D, Smyth N, Power E, Hiom S, Peake M, Wardle J. Knowledge of lung cancer symptoms and risk factors in the UK: development of a measure and results from a population-based survey. *Thorax* 2012;**67**:426-432.

Simon AE, Forbes L, Boniface D, Warburton F, Brain KE, Dossaix A, Donnelly M, Haynes K, Hvidberg L, Lagerlund M, Petermann L, Tishelman C, Vedsted P, Vigmostad MN, Wardle J, Ramirez AJ. An international measure of awareness and beliefs about cancer: development and testing of the ABC. *BMJ Open*, 2012;**2**:e001758.

Siriwardena AK, Siriwardena AM. Easily missed? Pancreatic cancer. *BMJ*, 2014;**349**:g6385.

Stapley S, Peters TJ, Neal RD, Rose PW, Walter FM, Hamilton W. The risk of oesophago-gastric cancer in symptomatic patients in primary care: a large case-control study using electronic records. *British Journal of Cancer*, 2013;**108**:25-31.

Stapley S, Peters TJ, Neal RD, Rose PW, Walter FM, Hamilton W. The risk of pancreatic cancer in symptomatic patients in primary care: a large case-control study using electronic records. *British Journal of Cancer*, 2012;**106**:1940-1944.

Taylor A, Stapley S, Hamilton W. Jaundice in primary care: a cohort study of adults aged >45 years using electronic medical records. *Family Practice*, 2012;**29**:416-420.

Toftegaard B, Bro F, Vedsted P. A geographical cluster randomised stepped wedge study of continuing medical education and cancer diagnosis in general practice. *Implementation Science*, 2014;**9**:1-13.

Vedsted P, Olesen F. A differentiated approach to referrals from general practice to support early cancer diagnosis – the Danish three-legged strategy. *British Journal of Cancer*, 2015;**112**:S65–S69.

Walker S, Hamilton W, Hyde C. Quantification of the risk of breast cancer in symptomatic primary care patients. *European Journal of Cancer Care*, 2014;**23**:S1-27.

Walker S, Hyde C, Hamilton W. Risk of uterine cancer in symptomatic women in primary care: case-control study using electronic records. *British Journal of General Practice* 2013;**63**:e643-e648.

Walter FM, Mwaka A, Neal RD. Achieving earlier diagnosis of symptomatic cervical cancer. *British Journal of General Practice* 2014;**64**:495-6.

Walters S, Maringe C, Butler J, Rachet B, Barrett-Lee P, Bergh J, Boyages J, Christiansen P, Lee M, Warnberg F, Allemani C, Engholm G, Fornander T, Gjerstorff ML, Johannesen TB, Lawrence G, McGahan CE, Middleton R, Steward J, Tracey E, Turner D, Richards MA, Coleman MP, ICBP Module 1 Working Group. Breast cancer survival and stage at diagnosis in Australia, Canada, Denmark, Norway, Sweden and the UK, 2000-2007: a population-based study. *British Journal of Cancer*, 2013a;**108**:1195-1208.

Walters S, Maringe C, Coleman MP, Peake MD, Butler J, Young N, Bergström S, Hanna L, Jakobsen E, Kölbek K, Sundström S, Engholm G, Gavin A, Gjerstorff ML, Hatcher J, Johannesen TB, Linklater KM, McGahan CE, Steward J, Tracey E, Turner D, Richards MA, Rachet B. Lung cancer survival and stage at diagnosis in Australia, Canada, Denmark, Norway, Sweden and the UK: a population-based study, 2004–2007. *Thorax*, 2013b;**68**:551-64.

Walters S, Maringe C, Butler J, Brierley JD, Rachet B, Coleman MP. Comparability of stage data in cancer registries in six countries: Lessons from the International Cancer Benchmarking Partnership. *International Journal of Cancer*, 2013c;**132**:676-685.

Weller D, Vedsted P, Rubin G, Walter FM, Emery J, Scott S, Campbell C, Andersen RS, Hamilton W, Olesen F, Rose P, Nafees S, van Rijswijk E, Hiom S, Muth C, Beyer M, Neal RD. The Aarhus statement: improving design and reporting of studies on early cancer diagnosis. *British Journal of Cancer*, 2012;**106**:1262-1267.

Welsh Cancer Intelligence and Surveillance Unit. Cancer in Wales. A summary report of the population incidence, mortality and survival – includes new 2013 data released as Official Statistics on 03 February 2015.

Welsh Government. Together for Health – Cancer Delivery Plan: our vision. Welsh Government, Cardiff: 2012.

Welsh Government. Together for Health cancer Delivery Plan. Annual Report 2014. Welsh Government, Cardiff: 2014.

Welsh Government. Our plan for a primary care service for Wales up to March 2018. Welsh Government, Cardiff: 2015.

Whitaker K, Scott SE, Wardle J. Applying symptom appraisal models to understand socio-demographic differences in responses to possible cancer symptoms: A research agenda. *British Journal of Cancer* 2015;**112**:27-34.

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## 11. Appendix 1. The 'deliverable'

A plan to improve cancer outcomes in Wales through earlier diagnosis. This will outline a number of potential initiatives over the next 3-5 years. This is likely to include:

- Consideration of a Welsh Early Diagnosis Initiative (WAEDI) – based upon the English and Scottish models
- Implementation of issues coming out of ICBP Modules 3 & 4 – based upon international best practice (e.g. access to diagnostics, development of pathways and evaluation of pilots).
- Collaboration with WCISU on Module 5 of International Cancer Benchmarking Partnership for Wales
- Working with WCISU regarding outputs and reporting (especially in relation to primary care issues).
- Analysis of observatory / WCISU data (especially in relation to primary care issues).
- Development of recording of primary care data within WICSU for example the measurement of cancer delays (and diagnostic routes including emergency presentations) in Wales and ongoing monitoring over time.
- Significant Event Audits to be included in QoF / QP 2014-15 and input into design and data collection

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