Improving diagnostic pathways for patients with vague symptoms

Accelerate, Coordinate, Evaluate (ACE) Programme
An early diagnosis of cancer initiative supported by:
NHS England, Cancer Research UK and Macmillan Cancer Support

ACE Vague Symptoms Cluster
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Thank you to Andrew Millar for reviewing this report.

**About the ACE Programme**

The Accelerate, Coordinate, Evaluate (ACE) Programme is an early diagnosis of cancer initiative focused on testing innovations that either identify individuals at high risk of cancer earlier or streamline diagnostic pathways. It was set-up to accelerate the pace of change in this area by adding to the knowledge base and is delivered with support from: NHS England, Cancer Research UK and Macmillan Cancer Support; with support on evaluation provided by the Department of Health’s Policy Research Units (PRUs).

The first phase of the programme consisted of 60 projects split into various topic-based clusters to facilitate evidence generation and learning. The second phase (pilots live January 2017) comprises five projects exploring multidisciplinary diagnostic centre (MDC) – based pathways. The learning from ACE is intended to provide ideas and evidence to those seeking to improve local cancer services. The evaluations and findings are produced independently, and are therefore, not necessarily endorsed by the three supporting organisations.
Executive Summary

Introduction

This report summarises learning from the ACE Vague Symptoms cluster, a series of projects aiming to explore ways of achieving earlier diagnosis of cancer for patients that are currently not served well by existing referral guidelines, processes and pathways.

Two groups of patients were addressed by the cluster:

1. Patients that present with non-specific but concerning symptoms that do not indicate a likely primary tumour site, or meet the criteria for a site specific urgent referral pathway for cancer
2. Patients that present late to their GP with new suspected cancer, but the GP regards the patient as already too ill to wait for a two week wait (2WW) referral or is unsure of the primary cancer site

Purpose

The aim of the projects was to monitor and evaluate different approaches in order to make recommendations to commissioners and providers. The main report details pathway interventions and recommendations from audits designed to improve the diagnostic pathway for patients with non-specific but concerning symptoms.

Each of the nine projects involved took one of the following approaches:

- **Intervention-based** – where a new service or pathway was introduced to improve the diagnostic pathway for patients with vague symptoms, ensuring access to rapid diagnostics and specialist support
- **Audit-based** – where an audit was undertaken of the diagnostic journey of patients, in order to identify areas needing improvement and inform future service development

Context


Some cancers can be more difficult to diagnose, in particular those that present with vague symptoms. The term ‘vague’ refers to non-specific but serious symptoms such as *unexplained weight loss and/or appetite loss, non-specific abdominal discomfort or pain, fatigue and sweats of unexplained aetiology*. Some symptoms or combinations of symptoms can have a number of causes and can also be symptoms of several types of cancer. The risk for each individual cancer may be low, but the total risk of cancer of any type may be higher (National Institute for Health and Care Excellence, 2015).
Harder to suspect cancers such as myeloma, pancreatic, stomach, and lung cancers are typified by non-specific presenting symptoms. This can result in an extended diagnostic interval in comparison to easier to suspect cancers such as melanoma and breast (Irving G, 2013). The resulting delay in diagnosis and subsequent treatment can result in poorer clinical outcomes (McPhail S, 2015), as well as a poor experience for the patient (Mendonca SC, 2016).

**Key Findings**

1) **Time to diagnosis:** The time to diagnosis can be improved for patients with non-specific but concerning symptoms that do not meet current urgent referral guidelines, by providing vague symptom-based diagnostic pathways and by innovations to streamline the process. For patients with new suspected cancer that are too ill to wait for a 2WW referral, a referral to a diagnostic clinic (within 24hrs) can provide rapid access to the appropriate diagnostic tests other than via A&E. Speeding up the time to diagnosis will improve the experience for the patient and should enable appropriate treatment to start earlier.

Projects utilised a number of initiatives to speed up the diagnostic process. Whilst these have shown benefits for the cohort of vague symptoms patients, there are aspects that could also be used to improve standard urgent referral pathways, for example:

- One-stop diagnostic clinics (e.g. jaundice clinic)
- Electronic referral advice from radiology to GP
- ‘Hot’ (same day) reporting
- Reduced time from investigations to follow-up appointments, with clinical nurse specialists (CNS) being the point of contact for urgent results
- Flexible follow-up, including use of telephone follow up when results are unremarkable, to minimise number of clinic appointments
- Improved communication between GP and hospital

2) **Stage at diagnosis:** Where staging data was available from the pilot projects, the majority of cancers identified were stage III or IV. Where staging data was not available, the health of patients was indicative of late presentation, as many were only suitable for palliative care. The results support the need for more initiatives to help patients recognise the need to have their symptoms investigated.

One project did pick up several lung cancers (stage I–III) on CT following normal chest x-ray (CXR). Data was too limited to draw firm conclusions, but anecdotally this supports evidence from trials suggesting low-dose CT has greater sensitivity for the early diagnosis lung cancer over standard CXR (National Lung Screening Trial Research Team, 2013).

3) **Other diagnoses:** As well as identifying cancer, the pilot projects picked up a significant number of patients with other serious non-malignant disease. Some of these were likely incidental findings, whereas others were related to the original presenting symptoms.
Gastroenterology-related pathology was the most common finding including pancreatitis, chronic liver disease, and diverticulitis. Cardiac disease, respiratory pathology and musculoskeletal pathology were also found. The results suggest that symptom-based diagnostic pathways may have a broader role in diagnosing a wide range of conditions where differential diagnosis is challenging.

4) **Patient experience:** From the three projects that undertook a patient experience survey, responses were predominately positive in terms of how patients rated their care; the length of time they had to wait for tests and appointments; the information they received and whether they were likely to recommend the service to friends and family.

5) **Conversion rates:** There were a range of conversion rates found by projects, dependant on the referral criteria. Pathways for patients who were more seriously ill had higher conversion rates, such as Chelsea and Westminster [A52] 47%. Pathways for patients presenting with non-specific vague symptoms had lower conversion rates, as would be expected when trying to increase detection rates of earlier stage cancer. For example, the Suffolk weight loss pathway [A81] achieved a conversion rate of 6.5%.

6) **Cost-effectiveness:** The projects reported here did not directly measure costs. However, innovations to streamline pathways and reduce unnecessary appointments or diagnostic tests should theoretically lower costs. An economic evaluation will be undertaken of five pilot multi-disciplinary diagnostic centre based pathways for patients with non-specific symptoms, as part of the second phase of the ACE Programme.

7) **Financial drivers:** The ACE Programme identified competing financial drivers in different parts of the healthcare system that could adversely impact the implementation of cost-saving service improvements across primary and secondary care. Clinical commissioning groups (CCGs), NHS England and the Department of Health wish to introduce efficiencies and lower costs by reducing hospital activity, mainly by avoiding unnecessary appointments and diagnostic tests. Conversely, hospital services need to show that any new service or pathway will retain or increase income for the hospital trust, by increasing clinical activity.
Recommendations

1) NHS commissioners and providers should consider the need for novel diagnostic pathways for patients that present with non-specific but concerning symptoms, who do not meet current urgent referral guidelines for suspected cancer, in order to ensure timely diagnosis for these patients. This could comprise improved access to diagnostics from primary care, or referral to diagnostic centres. ACE Wave 2 is exploring the concept of multi-disciplinary diagnostic centres (MDCs) for this cohort of patients and will provide further evidence to inform the best approach.

2) Rapid access to diagnostics should be available for patients with suspected cancer who are too ill to wait for a 2WW referral, to avoid referral into A&E. Approaches could include ensuring rapid direct access to diagnostics from primary care, or fast track referral to access secondary care diagnostic clinics / multidisciplinary diagnostic centres.

3) Providers should explore options to streamline local diagnostic pathways for cancer such as: one-stop diagnostic clinics, improved communication and electronic advice from secondary care to GPs, ‘hot’ (same day) reporting, flexible follow-up, increased use of clinical nurse specialists as coordinators of patient care and to act as a point of contact for urgent results.

4) The merit of symptom based diagnostic pathways should be considered for a broader range of diseases other than just cancer, for patients that present with non-specific symptoms and where differential diagnosis is challenging. The ACE Wave 2 MDC pilots will track both cancer, and other non-cancer diagnoses, contributing evidence on the benefits or otherwise of this approach.

5) There should continue to be a focus on innovations in screening to achieve the early detection of cancer, and patient awareness initiatives to support early presentation to primary care clinicians. Earlier presentation at primary care is likely to enhance the benefit of faster diagnostic pathways on the stage at diagnosis.

6) Where symptoms based diagnostic pathways are implemented, the best payment structure should be explored, considering a best-practice tariff for hospital Trusts that supports rapid diagnosis by a reduction in unnecessary appointments and diagnostic tests.
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1. Introduction

This report summarises learning from the ACE Vague Symptoms Cluster, a series of projects aiming to explore ways of achieving earlier diagnosis of cancer for patients that are currently not served well by existing referral guidelines, processes and pathways.

The term ‘vague’ symptoms refers to non-specific but serious symptoms such as unexplained weight loss and/or appetite loss, non-specific abdominal discomfort or pain, fatigue and sweats of unexplained aetiology. Some symptoms or symptom combinations may be features of several different cancers. For example unexplained weight loss can be a symptom of colorectal, gastro-oesophageal, lung, prostate, pancreatic and urological cancer. For some of these non-specific symptoms, the risk for each individual cancer may be low, but the total risk of cancer of any type may be higher (National Institute for Health and Care Excellence, 2015).

Invitations to participate in the ACE Programme commenced in June 2014. Two groups of patients were identified for inclusion in the Vague Symptoms cluster, where improvements in the diagnostic pathway were warranted and where local initiatives were being put in place to address shortfalls:

1. Patients that present with non-specific but concerning symptoms that do not indicate a likely primary tumour site, or meet the criteria for a site specific urgent referral pathway for cancer

2. Patients that present late to their GP with new suspected cancer, but the GP regards the patient as already too ill to wait for a 2WW referral or is unsure of the primary cancer site

The aim of the ACE Vague Symptoms cluster was to monitor and evaluate these local projects, in order to make recommendations to commissioners and providers. This report includes details of pathway interventions and recommendations from audits designed to improve the diagnostic pathway for these groups of patients. A resource pack to support local implementation is available as a supplement to this report.

2. Context

Achieving earlier diagnosis of cancer as a means to improving survival, reducing mortality and improving quality of life is a key challenge identified in Achieving World Class Cancer Outcomes: A Strategy for England 2015-2020 (Independent Cancer Taskforce, 2015). Earlier diagnosis makes it more likely that patients will receive treatments such as surgery and radiotherapy which contribute to the majority of cases where cancer is cured.
Some cancers can be more difficult to diagnose, in particular those that present with vague symptoms (Rubin G, 2015). Some symptoms or combinations of symptoms such as abdominal pain, weight loss, or fatigue can have a number of causes and can also be symptoms of several types of cancer (National Institute for Health and Care Excellence, 2015).

Harder to suspect cancers such as myeloma, pancreatic, stomach, and lung cancers are typified by non-specific presenting symptoms. This can result in an extended diagnostic interval in comparison to easier to suspect cancers such as melanoma and breast (Irving G, 2013). A systematic review found an association between shorter times to diagnosis and more favourable outcomes for some cancers including colorectal and pancreatic (Neal RD, 2015). A delay in diagnosis and subsequent treatment can result in poorer clinical outcomes (McPhail S, 2015). A negative association has also been found between multiple pre-diagnostic appointments in primary care, before referral to a specialist, and the experience of subsequent cancer care (Mendonca SC, 2016).

The urgent referral process for suspected cancer (‘two-week wait’ (2WW) referral) was introduced in 2000 to speed up the diagnosis of cancer (Department of Health, 2000), and allows GPs to refer the patient quickly to a tumour specific diagnostic pathway, based around symptom aetiology. However, in England, only 30% of cancers are diagnosed through this route (National Cancer Registration & Analysis Service, 2015). Research from Denmark (Jensen H, 2014), found that just under half of cancer patients (48 per cent) presented with clear symptoms of a particular type of cancer, whilst the other 52% presented with a range of non-specific symptoms.

If patients present with vague symptoms, it can be difficult to identify the correct referral pathway the first time. Patients may be sent down multiple different pathways, before the correct diagnostic test and consequential diagnosis is reached (Green T, 2015).

A further complication of a site specific urgent referral approach is that patients that present to their GP with early stage cancer may have less clear symptoms, before ‘red flag’ symptoms for a specific urgent referral pathway are indicated. A Danish study found that patients with ‘vague’ symptoms had a 34 days longer median time to diagnosis than patients with ‘alarm’ symptoms (Jensen H, 2014). By the time someone meets the criteria for 2WW symptoms, the cancer has often become advanced (Green T, 2015), so the use of site specific urgent referral pathways could potentially delay diagnosis for earlier stage cancer patients presenting with vague symptoms.

Updated NICE guidelines for suspected cancer referral were introduced in June 2015 (National Institute for Health and Care Excellence, 2015) to try and address these shortfalls. The new guidance aims to support earlier diagnosis by lowering the average threshold for referral for adults based on symptom presentation from the previous 5% (in 2005 guidelines) to 3% in the 2015 version. The urgent referral pathway for suspected cancer (2WW referral) however, still requires the GPs to identify a site specific pathway.
The 2015 NICE guideline for suspected cancer recognition and referral (National Institute for Health and Care Excellence, 2015) also recommends that English GPs have direct access to diagnostic tests to investigate symptoms of cancer that do not meet the criteria for urgent referral. An audit of 533 English GPs, conducted at the time of release of the new guidance found that, whilst the majority of GPs reported direct access to x-ray and ultrasound, there is limited access, and wide geographical variation, in access to the majority of imaging tests such as CT scans, gastroscopy or MRI (Nicholson BD, 2016).

The ACE Programme aimed to implement and evaluate initiatives to further improve the diagnostic process for patients that present to primary care with non-specific but concerning symptoms, to ensure a timely diagnosis for these patients.

The second category of patients addressed by the Vague Symptoms cluster includes patients that present late to their GP with serious symptoms that could be cancer, who are already too ill to wait for an urgent cancer referral and where the primary tumour site is unclear. There is currently a lack of options for rapid investigation under current managed routine or urgent specialist referral routes. GPs often revert to referring these patients to accident and emergency, in order to ensure that the patient is seen quickly and gains access to diagnostic tests (Black G, 2015). Emergency presentations of cancer are associated with significantly poorer relative survival than other routes to diagnosis (Elliss-Brookes L, 2012), (National Cancer Intelligence Network, 2013) and worse patient experience (Black G, 2015).

The 2015 NICE cancer referral guideline (National Institute for Health and Care Excellence, 2015) has tried to address this by introducing ‘very urgent referrals’ for diagnostic tests for some symptoms, where a patient should be seen within 48 hours. Theoretically this should lead to a reduction in cancers diagnosed via an emergency route; however a recent analysis of GP access to diagnostic tests found that many GPs could not access tests within the timescales recommended by NICE (Nicholson BD, 2016).

Projects within the Vague Symptoms cluster aimed to address the shortfalls in current services to ensure rapid and appropriate diagnostic pathways for patients with new suspected cancer who are too ill to wait for a 2WW referral.
3. ACE Vague Symptoms Projects

The cluster comprised nine projects exploring ways of streamlining the diagnostic pathway for patients that present with concerning, but non-site specific cancer symptoms and are summarised in Figure 1.

**Figure 1: Map of ACE projects focused on developing effective diagnostic pathways for patients with Vague Symptoms**
The projects were of two types:

- **Intervention-based studies** – where a new service or pathway was introduced to improve the diagnostic pathway for patients with vague symptoms, ensuring access to rapid diagnostics and specialist support.

- **Audit-based studies** – where an audit was undertaken of the diagnostic journey of patients, in order to identify areas needing improvement and inform future service development

**a) Intervention-based studies**

Projects explored new pathways for patients with a particular non-specific symptom such as weight loss [A81 Suffolk], a range of non-specific symptoms [A23 London Cancer, A57 St. Helen’s and Knowsley, A38 Airedale] or aimed at a particular tumour group such as pancreatic cancer [A70 Manchester].

Some of the projects achieved this through broadening the scope of their cancer of unknown primary (CUP) or acute oncology services to incorporate a wider group of patients [A57 St. Helen’s and Knowsley, A52 Chelsea and Westminster]. Alternatively, London Cancer [A23] set-up a multi-disciplinary diagnostic centre (MDC), where a patient could undergo a number of tests on the same day, or within a short period, for patients with weight loss and vague abdominal symptoms.

ACE is further exploring the concepts of MDCs as part of the ACE Wave 2 programme, with a further nine MDC sites planned across the country.

**b) Audit-based studies**

Two projects audited the patient journey from presentation in primary care to diagnosis in secondary care, in order to identify areas for improvement in adults [A83 Slough], and teenagers and young adults [A62 Bristol], the latter highlighting the challenges faced by this particular group of patients.
4. Key Findings

The key findings from across the Vague Symptoms cluster are summarised below. A summary of each project detailing the approach and outcomes is given in Appendix A. For further information all projects have produced detailed individual reports that can be found at www.cruk.org/ace.

(a) Faster diagnosis and treatment

The Department of Health sets national maximum cancer waiting time standards for NHS providers in England to meet, for time from: GP referral to first outpatient attendance (14 days); decision to treat to first definitive treatment (31 days); and, referral to first treatment (62 days) (NHS England, 2015).

Projects in the Vague Symptoms cluster demonstrated that significant benefits could be gained over cancer waiting time standards, leading to a quicker diagnosis and earlier elective care, by streamlining diagnostic pathways for vague symptoms patients that are known to often experience extended diagnostic intervals (Irving G, 2013).

Benefits were seen for two categories of patients:

- Those that presented to the GP with non-specific symptoms, where the GP had a suspicion that their symptoms could be due to cancer, but where the patient did not meet tumour specific urgent referral criteria
- Those where the GP suspected cancer, but regarded the patient as already too ill to wait for a 2WW referral or was unsure of the primary tumour site

The Manchester Cancer one-stop jaundice clinic [A70] provided same day imaging for presenting patients, 96% of which had a diagnosis within two weeks. The earlier diagnosis was instrumental in achieving earlier treatment for pancreatic cancer. Time from ultrasound and CT scan to surgery decreased from a median of 57 and 33 days pre-pathway to 13 and 9 days respectively post pathway.

Airedale [A38] achieved a mean time from primary care referral to diagnosis of three weeks, demonstrating the added value of a radiologist in the decision making process, by ensuring the right first test. At the London Cancer multi-disciplinary diagnostic centre [A23], 80% of patients were informed of their cancer diagnosis within 28 days, with a mean time to diagnosis of just 19.6 days (range 4 to 47 days).

Interestingly, London Cancer [A23] found that persuading patients to attend an appointment on the next working day was a challenge. Despite high levels of appropriate referrals from primary care, it was clear that not all patients wanted to be seen within 36 hours of referrals.
The Chelsea and Westminster Acute Diagnostic Oncology Clinic [A52 ADOC], for patients that were too ill to wait for a 2WW referral, reduced the time from GP referral to cancer diagnosis (mean - 7 days), by minimising the wait to see a consultant, same day tests and results, proactive chasing of results and flexible follow-up appointments or phone calls. ADOC achieved a mean of just 16.4 days from referral to treatment.

Projects utilised a number of initiatives to speed up the diagnostic process. Whilst these have shown benefits for the cohort of vague symptoms patients, there are aspects that could also be used to improve standard 2WW pathways, for example:

- One-stop diagnostic clinics (e.g. jaundice clinic)
- Electronic referral advice from radiology to GP
- ‘Hot’ (same day) reporting
- Reduced time from investigations to follow-up appointments, with clinical nurse specialists (CNS) being the point of contact for urgent results
- Flexible follow-up, including use of telephone follow up when results are unremarkable, to minimise number of clinic appointments
- Improved communication between GP and hospital

The time to diagnosis can be improved for patients with non-specific and concerning symptoms that do not meet current urgent referral guidelines for cancer, by providing vague symptom based diagnostic pathways and by innovations to streamline the process. For patients that are too ill to wait for a 2WW referral, a referral to a diagnostic clinic (within 24hrs) can provide rapid access to diagnostic tests other than via A&E. Speeding up the time to diagnosis will improve the experience for the patient and should enable appropriate treatment to start earlier.

(b) Stage at diagnosis

Diagnosing cancer at an earlier stage is associated with better outcomes for patients (McPhail S, 2015). Improvements in early diagnosis are likely to be brought about primarily by screening programmes to identify asymptomatic cases, and also by encouraging early presentation of patients with symptoms to the healthcare system (Independent Cancer Taskforce, 2015). Improvements in the diagnostic pathway once patients present with symptoms could potentially help to reduce the number of cancers diagnosed at a late stage for the more difficult to diagnose cancers (Vedsted P, 2015).

Where staging data was available from the pilot projects, the majority of cancers identified were later stage (III or IV) [A52, A57]. Where staging data was not available, the health of patients was indicative of late presentation, as many were only suitable for palliative care [Airedale A38].
Patients that presented with vague symptoms (in particular weight loss and fatigue) typically represented an elderly population with comorbidities. In the St Helen’s and Knowsley vague symptoms pilot [A57], this was reflected in the fact that 21% of benign cases subsequently died within three months of initial referral; most commonly associated with chronic chest comorbidity and sepsis. In the Airedale pilot [A38], the majority of patients went on to palliative care. Similarly, the majority of patients who attended the Chelsea and Westminster ADOC [A52] were diagnosed at stage IV, which would be expected for this group of acutely ill patients.

Nevertheless, it is appropriate that all patients with cancer are diagnosed as soon as possible after presenting to doctors. Even for patients who did not go on to receive treatment, there is growing evidence that good supportive care, provided early to patients with advanced cancer, can improve quality of life, possibly lengthen survival and reduce the need for aggressive treatment near the end of life. This helps avoid or reduce the length of in-patient stays, and is known to reduce the costs of care (Temel JS, 2010).

The St Helen’s and Knowsley vague symptoms pathway [A57] did pick up several lung cancers (stage I–III) on CT following normal CXR. Considering the small size of the overall cohort it is not possible to draw conclusions, but anecdotally this supports evidence from trials suggesting low-dose CT has greater sensitivity for the earlier diagnosis of lung cancer over standard CXR (National Lung Screening Trial Research Team, 2013).

The pilot projects found that the majority of patients already had significant disease when they presented to their GP with ‘vague’ symptoms. This meant that in these cases, improvements in the diagnostic pathway were not reflected in earlier stage diagnosis.

The results support the need for further innovations in screening to achieve early detection of cancer, and more work is needed to help patients recognise the need to have symptoms investigated. Earlier presentation at primary care is likely to enhance the benefit of faster diagnostic pathways on the stage at diagnosis.

(c) Other diagnoses

As well as identifying cancer, the pilot projects also picked up a significant number of patients with other non-malignant disease. Some of these were likely to be incidental findings, whereas others were related to the original presenting symptoms. In the Airedale pilot [A38], 26 patients out of 89 had non-cancer pathology. Gastroenterology-related pathology was the most common finding including pancreatitis, chronic liver disease, and diverticulitis. Cardiac disease (congestive cardiac failure, cardiac ischaemia), respiratory pathology (interstitial lung disease, emphysema, chest infection) and musculoskeletal pathology (degenerative disc disease, spondylosis, and bursitis) were also found. The London Cancer MDC [A23] found that 12.6% patients had other significant non-malignant diagnosis (e.g. pancreatitis, colonic polyps, gallstones) and Suffolk [A81] found that weight loss could be an indicator for a wide range of illnesses.
St Helens and Knowsley [A57] noted that the majority of vague symptom referrals did not have cancer and several symptom-directed pathways emerged for onward referral:

- Elderly & comorbidity – Geriatrics
- Inflammatory bloods and history – Rheumatology
- Anaemia – Gastro/Haematology
- Non-specific (<70yrs) – the role of General Medicine

The results suggest that symptom based diagnostic pathways might have a broader role in diagnosing a wide range of conditions where differential diagnosis is challenging. Even if cancer is excluded, the non-specific nature of most tests used may result in earlier diagnosis of another underlying condition, which might also benefit from earlier intervention. With increasing numbers of patients presenting with co-morbidities a broader symptom based diagnostic approach may be appropriate.

(d) Patient experience

Patient experience has emerged as an outcome measure of equal importance to traditional health outcomes for patients. This view is emphasised by the Independent Cancer Taskforce in *Achieving World Class Cancer Outcomes: A Strategy for England 2015-2020* (Independent Cancer Taskforce, 2015), which aims to boost cancer survival and transform patient experience.

A patient experience survey was developed for use by projects across the cluster, led by Derek O Reilly, Consultant HPB Surgeon, as part of the Manchester Cancer Jaundice Pathway. The online Survey Monkey™ questionnaire comprised a series of 15 questions chosen from the NHS National Cancer Patient Experience Survey plus the NHS Friends & Family Test. Patient surveys were conducted by Chelsea and Westminster [A57], London Cancer [A23], and Manchester Cancer [A70] and can be found in individual project reports at www.cruk.org/ace.

For the three projects that undertook a patient experience survey, responses were predominately positive in terms of how patients rated their care; the length of time they had to wait for tests and appointments; the information they received and whether they were likely to recommend the service to friends and family.

(e) Conversion rates

There were a range of conversion rates found by projects, dependant on the referral criteria. Pathways for patients who were more seriously ill had higher conversion rates such as Chelsea and Westminster [A52] 47% and Manchester Cancer [A70] 24%. Pathways for patients presenting with non-specific vague symptoms had lower conversion rates, as would be expected when trying to increase detection rates of earlier stage cancer. Referral rates varied depending on local demographics and the exact referral criteria. The London MDC [A23] had a conversion rate of 3%,
Airedale [A38] 12.3%, St Helens and Knowsley [A57] 8%, and the Suffolk weight loss pathway [A81] 6.5%.

Further consideration is needed of the appropriate range of conversion rates for vague symptom cancer referral pathways. This will be explored as part of the ACE Wave 2 programme evaluating multidisciplinary diagnostic centre (MDC) based pathways.

(f) Cost-effectiveness

Innovations within the NHS need to be both clinically effective and cost effective to justify implementation. The projects reported here did not directly measure costs. However, innovations to streamline pathways and speed up the time to diagnosis by reducing unnecessary appointments or diagnostic tests should theoretically lower costs. An economic evaluation will be undertaken of five pilot MDC-based pathways for patients with non-specific symptoms, as part of the next phase of ACE.

(g) Financial drivers

As an adjunct to the main findings from the pilot projects, some projects commented on the existence of competing financial drivers in different parts of the healthcare system. Clinical Commissioning Groups (CCGs), NHS England and the Department of Health wish to introduce efficiencies and lower costs by reducing activity in secondary care, mainly by avoiding unnecessary appointments and diagnostic tests. Conversely, new hospital services need to demonstrate that a new service or pathway will retain or ideally increase income for the Trust, by increasing activity.

The Acute Diagnostic Oncology Clinic [A52] business case, for example, included that the service would:

- Generate funds for the Trust via increased outpatient volumes, investigations, outpatient appointments (using the multi-disciplinary team tariff)
- Attract additional downstream tariff income (e.g. surgery, chemotherapy) for patients

The conflicting financial drivers of trusts to generate income versus commissioners to reduce costs, could adversely impact the implementation of cost-saving service improvements across primary and secondary care. This should be addressed through the payment structure for provider trusts, possibly through a best-practice tariff for efficient diagnostic pathways.
5. Recommendations

1) NHS commissioners and providers should consider the need for novel diagnostic pathways for patients that present with non-specific but concerning symptoms, who do not meet current urgent referral guidelines for suspected cancer, in order to ensure timely diagnosis for these patients. This could comprise improved access to diagnostics from primary care, or referral to diagnostic centres. ACE Wave 2 is exploring the concept of multi-disciplinary diagnostic centres (MDCs) for this cohort of patients and will provide further evidence to inform the best approach.

2) Rapid access to diagnostics should be available for patients with suspected cancer who are too ill to wait for a 2WW referral, to avoid referral into A&E. Approaches could include ensuring rapid direct access to diagnostics from primary care, or fast track referral to access secondary care diagnostic clinics / multidisciplinary diagnostic centres.

3) Providers should explore options to streamline local diagnostic pathways for cancer such as: one-stop diagnostic clinics, improved communication and electronic advice from secondary care to GPs, ‘hot’ (same day) reporting, flexible follow-up, increased use of clinical nurse specialists as coordinators of patient care and to act as a point of contact for urgent results.

4) The merit of symptom based diagnostic pathways should be considered for a broader range of diseases other than just cancer, for patients that present with non-specific symptoms and where differential diagnosis is challenging. The ACE Wave 2 MDC pilots will track both cancer, and other non-cancer diagnoses, contributing evidence on the benefits or otherwise of this approach.

5) There should continue to be a focus on innovations in screening to achieve the early detection of cancer, and patient awareness initiatives to support early presentation to primary care clinicians. Earlier presentation at primary care is likely to enhance the benefit of faster diagnostic pathways on the stage at diagnosis.

6) Where symptoms-based diagnostic pathways are implemented, the best payment structure should be explored, considering a best-practice tariff for hospital trusts that supports rapid diagnosis by a reduction in unnecessary appointments and diagnostic tests.
6. References


7. Abbreviations

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<td>ADOC</td>
<td>Acute Diagnostic Oncology Clinic</td>
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<td>AO</td>
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<td>BHRUT</td>
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<td>Ca</td>
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<td>CCG</td>
<td>Clinical Commissioning Group</td>
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<td>CNS</td>
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Contact ACE

If you have any queries about ACE, please contact the team at: ACEteam@cancer.org.uk
In addition, you can visit our webpage: www.cruk.org/ace where we will publish news and reports.

The ACE Programme

Accelerate, Coordinate, Evaluate
Appendix: Vague Symptom
Project Summaries
### A7 Acute Oncology Project
**Bristol, North Somerset and South Gloucestershire**

#### Overview
The ACE Acute Oncology project set out to provide a more efficient pathway with more timely diagnosis for patients.

#### Context
This project was identified by the members of the Bristol, North Somerset and South Gloucestershire (BNSSG) Cancer Group in Autumn 2014, as an area for focus due to feedback from the emergency significant event audits run by South West Strategic Clinical Network Early Diagnosis Group, need to improve Peer Review Measures for Acute Oncology and the need to initiate and improve the 2WW CUP clinics that had been recently launched.

The project identified three key strands of work for focus:

- **Cancer of Unknown Primary Urgent Referral Pathway** - Development and commissioning of a single approach across BNSSG for Cancer of Unknown Primary (CUP) urgent referrals with evidence of cancer where there are no signs/symptoms to suggest the location of the primary cancer.

- **Acute Oncology Service Specification** - Refining and formalising of Acute Oncology (AO) Services across all three BNSSG providers, including support for patients with toxicity issues and formalising this in a single service specification for inclusion in provider contracts.

- **Vague Symptoms Pathway Proposal** - Clarification of the unmet need for patients with vague symptoms where cancer may be a differential diagnosis amongst other serious diseases and development of a service proposal for how this could be resolved locally.

#### Aim and Objectives

- Improve patient outcomes and experience for those patients in whom cancer is suspected but the specific cancer site is unknown;
- To improve the time from referral to symptom management, diagnosis and care plan for those patients with suspected cancer for which the specific cancer site is yet unknown;
- To improve patient outcomes through planned referrals to a single service rather than “bouncing” them around the system or having to be diagnosed in an emergency setting;
- To reduce the number of unnecessary investigations undertaken on patients whose care plan will not change irrespective of more accurate diagnosis;
- To develop the services with strong patient and carer input to ensure it is best meeting the needs of this patient population;
- Ensure that any future improvements/service changes support improved outcomes and experience for patients.
## Description of project

The project audited and reviewed existing practice in CUP and AO services across the region, recommended areas for improvement and developed service specifications and referral guidance.

## Results

**CUP Urgent Referral Pathway** – the project found that a number of different referral pathways for CUP existed across the regions and that the need to meet national requirements for 2WW meant that patients were being seen without appropriate diagnostics being done first. It emerged that this actually created delays in patients being seen and initiating effective clinical care. It was also recognised that there were small numbers being referred through this route and questionable there is no need to commission three separate clinics by three separate providers across the region.

**Acute Oncology Service Specification** - There had been an Acute Oncology service offered by each of the 3 providers for several years. It was identified that the current service spec did not reflect everything that the service currently offered and had not built in developments to ensure the service is aligned with national guidelines.

**Vague Symptoms Pathway** – the project recommended exploring the possibility of extending the referral criteria for existing services rather than commissioning something new, due to what was perceived as a relatively small patient’s cohort and to consider the following:

- Creation of a multi-disciplinary team (MDT) that includes GP with special interest, geriatrician, medical consultant and medical oncologist to pool their knowledge and consider results of diagnostics from a range of perspectives to ensure that there is consideration of significant but non-cancer diagnosis;
- Use of a ‘hot’ clinic approach to ensure that urgent access is available whenever required;
- Development of an advice and guidance option to allow GPs to discuss the patient in a timely manner to avoid unnecessary emergency admissions.

## Impact and Benefits

- Recommendation of a single streamlined urgent referral pathway for CUP at two (rather than three) providers and production of service specification and referral guidelines for GPs.
- Revised acute oncology service specification to meet national guidelines and for inclusion in contractual agreements with trusts.
A23 London Cancer MDC Pilot

Overview

The multidisciplinary diagnostic clinic (MDC) pilot aimed to provide a more structured diagnostic pathway for a defined group of patients with abdominal symptoms, thereby improving patient flow and avoiding unnecessary admissions. The project successfully set up one MDC in a teaching hospital and gained valuable insight into the requirements for future provision from a short-term implementation at a district general hospital.

Context

The time to diagnosis for patients with suspected cancer in the NHS is often excessive leading to unnecessary distress for patients and contributing to the poor survival rates in the UK compared to Europe. The 2WW route was instituted to manage this process but despite this development, just under half of cancer patients are diagnosed though 2WW pathways, with many patients diagnosed after presentation to emergency services – ranging from 17-29% at trusts across our system. In recent work by London Cancer that evaluated 963 patients with cancer first diagnosed through an emergency presentation route across 11 A&Es, the commonest diagnoses were lung (33%), colorectal (18%) and upper GI cancers (18%). In one third of cases with analysis of the preceding primary care pathway, the GP had acted correctly to achieve urgent referral yet the patient had ended up in A&E. Cancer patients diagnosed following an emergency presentation have poorer outcomes than those that receive their diagnosis following a managed referral, even when controlling for other factors.

A high proportion of cancers, including oesophageal, gastric, pancreatic, biliary, liver, colorectal, uterine and cervical cancers, commonly present with abdominal symptoms, which comprise an estimated 15% of primary consultations. However, only a minority are due to cancer. As a result, each GP is likely to see only a handful of abdominal tumours each year and for pancreatic cancer this figure is once every five years. Many patients who are diagnosed with cancer have often had symptoms for many months and have often seen a GP on several occasions before a diagnosis is reached. The implementation of Denmark’s fast-track programme for suspected head and neck cancers significantly improved time to diagnosis: from a median of 20 days in 1992, then 17 days in 2002, to 13 days in 2010.

Aim and Objectives

The overarching aim of the project was to improve patient survival, experience, and costs associated with abdominal cancer through the following objectives:
1. Shorten interval from presentation to diagnosis
2. Decrease use of inpatient beds during cancer diagnosis
3. Reduce the number of accident & emergency (A&E) or GP visits before a cancer diagnosis
4. Improved patient experience on the cancer diagnostic pathway
5. Develop a system to improve diagnostic stage and survival in abdominal cancer
Description of new pathway or service

Core Principles of MDC pilot

The MDC service is an out-patient service designed for ambulatory patients needing diagnosis and either treatment or referral within a few days of presentation to primary or secondary care. Clinical decisions are taken by senior specialists who are responsible for assessing patients and, in due course, provide advice and guidance to primary care, sanctioning ‘straight-to-test’ where appropriate and, as a future service development, assessing referrals from novel routes such as self-referral and referrals from pharmacies. The MDC works to the following core principles:

a) **Access** – open to primary and secondary care

b) **Managed referral process** – defined criteria that includes worrying but non-specific, ‘grey area’ symptoms – referral data sets are mandated.

c) **Specialist decision making** – senior clinicians available daily – usually the post-take specialist unless otherwise arranged to triage and direct patient care.

d) **Administrative and Pathway Support** – improve clinical effectiveness by provision of pathway coordinators (Band 4) providing support to patients and assistance to clinicians as well managing data collection, communication and performance monitoring.

e) **Close links to key departments and individuals to** – clinical nurse specialists, MDT coordinators, A&E, radiology, endoscopy, theatres, acute oncology service, specialist centres.

Under this model, patients are seen within five working days of referral from primary care at a multidisciplinary service that provides appropriate specialist assessment and diagnostic testing, and to arrive at a definitive management plan within a rapid timescale.

Referral Guidance

Multidisciplinary diagnostic centre is designed for patients with a serious possibility of cancer (consider whenever the diagnosis is unclear) and EITHER

- Do not fit 2WW criteria (vague abdominal symptoms, two or more emergency presentation within one month), but in whom there is no obvious diagnosis or alternative pathway for care
 OR
- Fit 2WW criteria (proven weight loss, painless jaundice) but do not need admission or are too unwell to wait for 2WW clinic

Referral Criteria

1) **Painless jaundice** – either clinically obvious or bilirubin > 80 mmol/L, cause unknown

2) **Unexplained and proven weight loss** – More than 5% recent unexplained and proven weight loss; not previously investigated and with no likely benign diagnosis

3) **Suspicious but non-specific abdominal symptoms**, these should have lasted >3 weeks but < 6 months, and malignancy suspected in the differential
4) **Recurrent abdominal pain** - resulting in at least two visits to A&E or primary care within one calendar month, not previously investigated and without a likely diagnosis

The service at UCLH was launched at the end of June 2016, and is on-going. The MDC service was implemented at BHRUT between 14 September 2015 and 16 March 2016, with a 3 week pause over December holiday period.

**Results**

Between end of June 2015 to end of July 2016, 172 referrals were received at UCLH. The reasons of referral were vague abdominal symptoms (50%), weight loss (32%), weight loss with vague symptoms (11%), others without clear pathway (5%) and multiple A&E visits with vague symptoms (2%). 94% of patients completed the pathway and received a diagnosis; 3% were discharged following multiple cancellations & ‘did not attends’, and 3% of patients requested to be discharged or were not suitable for the pathway.

**Clinical Outcome**

Overall five of 207 (2.4%) patients assessed had a cancer diagnosis. In addition we found 12.6% patients with a significant non-malignant diagnosis. The conversion rate is low but comparable to the 3% threshold for new NICE Suspected cancer: recognition and referral guidance (NICE NG12), as well as other UK-based research on risk of having cancer given a single alarm symptom (Jones R et al 2007, Hamilton W 2009). Given that the referral criteria were mainly for very vague symptoms we feel this is appropriate. The Danish MDC model has a 16.2% conversion rate (Ingeman ML et al 2015) with patients referred only after suspected cancer has been identified on an investigation rather than suspicion based on symptom alone. 80% of patients were informed of their cancer diagnosis within four weeks of referral (mean 19.6 days, ranges 4 to 47 days).

In the initial five months of the pathway at UCLH, it became clear that persuading patients to attend an appointment in the next working day is a challenge. Despite high levels of appropriate referrals from primary care at UCLH, it was clear not all patients want to be seen within 36 hours of referrals.

**Impact and Benefits**

The chief benefit of this Wave 1 implementation has been the proven feasibility of MDC implementation with great patient satisfaction and pathway metrics. This pathway is thus ready to deliver the proposed 28 day diagnostic pathway for those referred to the MDC.

**Outcome**

The next steps are to implement the MDC in other trusts as part of the Wave 2 ACE program and for additional indications.
References


A38 Electronic advice and Referral to radiology for Suspected Cancer - Airedale, Wharfedale & Craven

**Overview**

The project established and evaluated a new electronic referral system from GPs to radiology in order to get advice on the most suitable imaging for a patient with suspected cancer presenting with vague symptoms.

**Context**

This project was established after consultation with local GPs and Airedale Hospital Radiology Department as a result of difficulties experienced in accessing the most suitable imaging for such patients under an urgent timescale.

Whilst Airedale, Wharfedale and Craven’s (AWC) CCG was performing better than the England average for one year survival rates at 70% at the initiation of the project (2014), it was acknowledged that patients who presented with vague symptoms of cancer did less well overall in one year survival terms and often did not have an obvious pathway of investigation to be referred into.

In the light of setting up a new malignancy of unknown origin fast track service it was apparent that GPs needed a system of accessing urgent advice on the best radiological investigation for patients with vague but concerning symptoms of possible cancer.

**Aim and Objectives**

The overall aim of the project was to enable GPs to send electronic referral advice requests to radiology and for this to be an urgent service so that the correct imaging could then be organised within two weeks.

In getting radiological advice it was hoped that the total number of investigations per patient would be reduced and thus expedite the patient pathway and encourage earlier diagnosis of cancer patients presenting with vague symptoms.

**Description of new pathway or service**

In order to establish the pathway it was necessary to create an electronic advice template within SystmOne. GPs provided clinical details and relevant past medical history along with a suggestion of the most appropriate imaging using the electronic advice template. The GP gained patient consent to share the patient record with the radiologist. The radiologist then replies within two working days with their suggestion of the most appropriate imaging.
All GPs were invited to a pathway training session by local radiologists and the CCG GP cancer lead. In addition the CCG GP cancer lead visited individual practices to share this pathway with the practice teams and also help GPs identify which patients would benefit from this service. The pathway was launched on 1st June 2015, initially for a 12 month period, following which the evaluation took place.

**Results**

During the 12 month period there were a total of 96 referrals for advice on optimal imaging for patients with suspected cancer who did not fit the 2WW criteria for any site specific pathway. Of these, there were five referrals which were not appropriate as they were for radiology advice on non-suspected cancer patients so are excluded from the results, together with two patients whose data could not be tracked.

In total 11 cases of cancer were identified. The mean time from primary care referral to diagnosis was three weeks. Seven cases were recurrences or cancer with metastasis including oesophageal, prostate and liver. Other malignancies were hepatocellular carcinoma, lymphoma, meningioma and suspected renal cancer. Among them five patients were referred for further investigation or treatment and six received palliative care.

30 patients out of 89 were reported as having no pathology after initial imaging = 34%. Of these patients, eight went on to have further referrals to other specialities for further tests.

Non-cancer pathology was found in 26 patients as summarised below:

**Non-cancer pathology found in 26 patients**

![Non-cancer pathology found in 26 patients](image)
### Impact and benefits

The results show that 91 patients were referred into this service as having a serious suspected cancer diagnosis with no obvious referral pathway to follow. From the results it has been shown that the conversion rate to cancer of 12.3% is in fact higher than the 2WW referral national average of 10%, so that it is reasonable to conclude that the types of patients being referred were appropriate.

The cohort than had a normal scan following the e-consult that went onto to have no further investigations was high at 66% suggesting strongly that the added value of a radiologist in the decision making process resulted in the right test on the first attempt.

### Outcome

AWC is going on to develop a multi-disciplinary diagnostic clinic as part of the ACE Wave 2 programme. This e-consult service has now been commissioned by the CCG as part of core business and will be in addition to the MDC based pathways for patients with vague symptoms.
### Overview

The purpose of the project was to test the feasibility of providing a rapid access out-patient clinic for patients with new suspected cancer, who are too ill to wait for a two week referral.

### Context

In England, 25% of all cancer patients are diagnosed with their disease as part of attendance at acute medical services such as the emergency department (ED), of these patients 60% will be admitted. This route to diagnosis is associated with a significantly poorer survival rate and worse patient experience, as compared to patients diagnosed through elective 2WW pathways. There is also an additional burden on already overstretched acute medical services.

The Acute Diagnostic Oncology Clinic (ADOC) was set up in the light of a drive to reduce the emergency presentation of cancers and in response to the findings of an earlier study, Cancer Diagnosis in the Acute Setting (CADIAS), conducted at Chelsea & Westminster Hospital and five other London Foundation Trusts. This study suggested that in up to 50% of patients with an acute new diagnosis of cancer, GPs refer patients to the ED, and in addition patients also present to the ED whilst waiting for planned appointments or tests. Conversations with GP stakeholders confirmed that some GPs use ED as a rapid means of assessment for patients who need to be seen, or have diagnostic tests, sooner than the 2WW referral allows. In this respect ED is seen as a ‘safe’ pathway into secondary care.

### Aim and Objectives

The purpose of this project was to establish and test the feasibility of:

- Providing a new rapid access out-patient clinic for patients with new suspected cancer
- Providing general practitioners (GPs) with an alternative to referring their patients to ED
- Expediting the diagnosis or exclusion of cancer for patients, who are too ill to wait for a two week referral

### Description of new pathway or service

The Acute Diagnostic Oncology Clinic (ADOC) was set up and run as an outpatient clinic for a one year period at Chelsea & Westminster NHS Foundation Trust embedded within the Acute Oncology Service using established ambulatory clinic facilities and services. The Clinic was publicised to and accepted referrals from the 120 GP practices within the surrounding four Clinical Commissioning Groups.

**Referral criteria:**
1. Clinical or radiological evidence to suspect new cancer
2. Too ill to wait for the two week referral clinic
3. Well enough to attend an outpatient clinic
4. Are 18 years or over
5. Aware that they may have cancer

Exclusion criteria:
1. Medical emergencies must be sent to the ED.
2. Cancers not treated within Chelsea & Westminster were directed to the nearest appropriate provision.

The aim of the clinic is for patients to be seen within 24 hours of GP referral, provide access to most investigations within three to five days (Monday to Friday) and work towards a preliminary diagnosis within one week.

The patient is assessed by an oncology clinical nurse specialist, and reviewed by a consultant oncologist at the first appointment. The patient attends diagnostic services, wherever possible, as an outpatient.

When cancer is confirmed, patients are referred directly to the appropriate multidisciplinary team (MDT) and entered onto the established tumour site specific clinical pathway.

When cancer is excluded, the patient is referred back to the GP with detailed information on tests and results, and where appropriate, suggestion for onward referral to other specialties. In some cases the ADOC team arranged onward urgent referrals.

**Results**

Results for 12 month period from June 2015 showed:
- 98% patients were reviewed within 24 hours of GP referral
- 7 day (mean) referral to diagnosis
- 48% of patients seen had a cancer diagnosis
- 16 days (mean) referral to treatment
- 73% of imaging investigations conducted at first appointment
- 67% results back the same day
- Reduced the need for in-patient admissions.
- Patient questionnaire showed high levels of patient satisfaction with waiting times and the quality of care provided for them and their family within ADOC.
## Estimated Eligible Population Size

- **Estimated eligible population size**: 500,000

## Referrals Made to Clinic

- **Referrals made to clinic**: 92 patients

## Referrals Accepted to Clinic

- **Referrals accepted to clinic**: 55%, 51 patients

## Outpatient Appointments for Patients Accepted in Clinic

- **Outpatient appointments for patients accepted in clinic**: 86 appointments

## Conversion Rate - Percentage of Patients Referred Diagnosed with Cancer

- **Conversion rate**: 47%, 24 patients

## Patients Reviewed Within 24 Hours of GP Referral

- **Patients reviewed within 24 hours of GP referral**: 98%

## GP Referral to First Appointment with Consultant

- **GP referral to first appointment with consultant**: 7.1 hours (mean); 6 days (SD)

## GP Referral to Cancer Diagnosis

- **GP referral to cancer diagnosis**: 7 days (mean); 6.1 days (SD)

## GP Referral to Treatment

- **GP referral to treatment**: 16.4 days (mean); 11.1 days (SD)

## Cancer Diagnosis to Treatment

- **Cancer diagnosis to treatment**: 8.9 days (mean); 11.8 days (SD)

## Patients Admitted as an Inpatient from 1st Clinic Appointment

- **Patients admitted as an inpatient from 1st clinic appointment**: 29%; 7 patients

## Length of In-Patient Stay (Patients Admitted at 1st Appointment)

- **Length of in-patient stay**: 11.8 days; 13.7 days (SD)

## Impact and Benefits

ADOC has shown that the cancer pathway can be improved for patients by identifying a specific patient population, working innovatively, with similar resources but to tighter timeframes to provide:

- Better patient experience
- Faster access to the service
- Faster diagnosis and treatment
- Fewer patient admissions.

## Outcome

ADOC now runs at Chelsea and Westminster as part of routine clinical services. Furthermore, it is planned to extend ADOC to the other Trust site within West Middlesex University Hospital.

The project won best poster presentation at the National Acute Oncology Conference 2016 and Macmillan national award for Professional Excellence in the Innovation category 2017.
### Vague Symptoms Pathway

#### Overview

The aim of the ACE pilot was to implement and evaluate a vague symptoms referral pathway from general practice to acute oncology in order to reduce emergency admissions and late presentation of cancer.

#### Context

St Helen’s and Knowsley (St H&K) NHS Trust is a large acute hospital and cancer unit that serves a population of 350,000 in Merseyside and Cheshire. The St H&K Acute Oncology (AO) service is particularly well developed and reviewed 684 emergency admissions in 2015 of which 109 (15%) represented a new diagnosis of cancer. The AO team has been at the forefront of developing pathways for carcinoma of unknown primary (CUP) and AO service development that encompasses alerts, fast track clinics, a joint AO/CUP MDT and effective communication across site specific MDTs. The changes have helped to deliver:

- A sustained reduction in hospital length of stay (LOS) for CUP patients by 50% (25 days to 11 days)
- A shift of emergency presentation of CUP to urgent OPD (90% ED to 50%)
- Increased active treatment delivery to CUP and early specialist palliative care input
- NICE guidance and AO service development

The CUP Pathway is typified by vague symptoms and poorly defined diagnostic pathways and the service improvements that have been delivered are underpinned by the two basic principles of **early imaging detection** and **early specialist review (oncology)**.

#### Aim and Objectives

The pilot aims were:

- To reduce emergency presentation of cancer in patients with vague symptoms where an established two week referral pathway does not exist
- To reduce late presentation of cancer in patients with vague symptoms where an established two week referral pathway does not exist
- To develop a managed pathway and improve patient and professional experience

#### Description of new pathway or service

**Vague symptoms pathway**

The pathway was integrated into existing hospital AO and Cancer services. Referral required practices to formally register their interest and refer according to defined eligibility criteria and to complete a minimum set of community- based diagnostics including blood tests and CXR prior to referral.
All referrals were triaged by an existing AO nurse specialist (with advice from consultant AO when needed). Eligible patients were given access to CT chest, abdomen and pelvis within 14 days of GP request. MDT review, incorporating the referral information and CT result, occurred at the existing weekly AO/CUP MDT.

**Results**

The report provides a 12 month evaluation of all vague symptoms patients commencing 24/12/14 and includes a 6 month follow up period. Of the 52 patients referred, 8% vague symptom referrals were deemed ineligible because of either their symptoms fitting an existing pathway or considered inappropriate due to on-going management in secondary care. Of the remaining patients, 8% of them were diagnosed with cancers by the VS pathway including Lung and CUP. The majority were late stage diagnosis and died within six months. The interval time between referral to treatment was from six to 67 days. Lung cancer patients had a previous normal CXR.

**None cancers – six month outcomes**

43 non-cancer patients were tracked in primary care for six months to capture additional outcomes for this group of patients. Of these non-cancer patients, the MDT outcomes were:

19% were diagnosed with one the following:
- Osteoporotic collapse of thoracic vertebra
- Rheumatoid arthritis flare
- Polymyalgia Rheumatica
- Colo-vesical fistula
- Common bile duct stone
- Depression

81% patients were not diagnosed with specific diagnosis and symptoms were not deemed significant at six months follow-up.

**Following MD T discussions of these 43 non cancer patients:**

21% patients underwent further tests as a consequence of the MDT outcome described as follows:
- PSA test and follow up
- Bone scan
- ERCP/MRCP
- EBUS and interval CT
- Interval CT
- Sigmoidoscopy
25% patients were signposted by the MDT to potential onward referral such as:

- Department of elderly medicine
- Rheumatology
- Respiratory
- Gastroenterology
- General surgery

(21%) patients died within three months of referral due to:

- Chest sepsis
- Congestive heart failure
- Unknown/other

**Impact and Benefits**

The success of the project has led to a local agreement to continue the pilot for a second year and has generated service plans for vague symptom and ‘direct to CT’ pathways in the two major university hospitals in central Liverpool.

**Outcome**

The recognition that the majority of patients do not have cancer has led to the strategic aim of developing joined up multidisciplinary diagnostic pathways (MDCs) within the hospital Trust. The vague symptom pathway and analysis will continue for a further 12 months to underpin MDC development.
The Too Young to Get Cancer project was a clinical audit and evaluation to map the diagnostic pathway of 16-24yr olds referred to the South West Teenagers and Young Adults (TYA) multidisciplinary advisory team at University Hospital Bristol. The aim was to build an evidence base to inform future research and design of potential interventions; and to improve the time to diagnosis and the diagnostic experience for TYA.

Cancer is the most common cause of disease-related death in young people in the United Kingdom (accounting for 9% of all deaths in males and 15% of all deaths in females aged 15–24) yet it is uncommon, accounting for less than 1% of cancers at all ages (CRUK, 2013). Despite the fact that there are limited data to link prolonged time to diagnosis (TTD) with adverse outcome, there is clear evidence that young people and their families highlight delay in achieving diagnosis as a major concern.

The project proposed that a better understanding of the referral pathways used by TYA patients across the regional network would help identify ways in which delays may be minimised in the future.

1. To better understand the referral pathways used by TYA with cancer across the South West
2. To define and inform the design of interventions to improve TDD in TYA cancer
3. To disseminate findings within the primary and relevant secondary care communities in the South West and highlight the presentation and appropriate referral of TYA with suspected cancer
4. To share lessons learned with other TYA services in England

The records of 104 teenagers and young adults referred to the TYA multidisciplinary advisory team at University Hospital Bristol over an 18 month period between October 2014 and April 2016 were audited.

The current status of each young person was verified by their TYA clinical nurse specialist (CNS) or other relevant healthcare professional. Following verification, any young person who was deemed inappropriate to contact was removed from the database. Permission was sought from all patients (or their next of kin if deceased) to access their records.
Bereaved families
The inclusion of deceased patients, if possible, was important for the integrity of the project. An individual, case by case approach was taken when contacting the next of kin (NOK) of a deceased young person. The healthcare professional identified to have a working relationship with the NOK was contacted, and a personalised letter was sent if it was thought appropriate to do so.

Data collection
Upon receipt of all relevant permissions, the project support manager interrogated primary care and hospital records to extract information relating to:
- Symptom presentation and consultation frequency in primary care
- Source of referral and point of entry to secondary care for the symptoms that led to a cancer diagnosis
- Evidence of prior contact with secondary care (e.g. outpatient and A&E services) before the episode resulting in the diagnosis
- Time to start of treatment

Analysis
The data was used to construct individual pathway maps for each young person, showing the transition between primary and secondary care displayed on a timeline. All individual route maps were reviewed by a clinical panel comprising expertise from primary and secondary care.

Results
Lymphoma was the most common diagnosis (28%). The other diagnostic groups were carcinoma (20%), germ cell tumour (10%), leukaemia (17%), brain/CNS (7%), bone sarcoma (7%), soft tissue sarcoma (6%), malignant melanoma (5%) and other (1%). Brain/CNS tumours were under-represented and in part reflect low patient numbers observed in the region during the recruitment period. Leukaemia patients were over-represented, which likely reflects duration of treatment.

Route to diagnosis
93% of TYA had contact with primary care in the period prior to diagnosis. First presentation relating to the cancer diagnosis was to primary care in 89% of evaluable pathways, compared to 7% presenting to A&E and 4% presenting to other healthcare professionals.

The panel evaluated whether cancer was suspected at first presentation. Of those presenting to primary care, cancer was suspected in 34% of cases. This varied by diagnostic group with evidence of cancer suspicion highest in germ cell tumours (i.e. young adults presenting with
testicular symptoms) at 67%. Cancer was not suspected at first presentation in any of the bone sarcoma patients.

45% of patients were referred via 2WW pathways, 38% presented as an emergency, 11% via GP referrals, 6% other outpatient routes and less than five patients were detected via screening. Of the patients presenting via an emergency route, 34% were deemed ‘potentially avoidable’ (i.e. that the referral could have been made earlier) and 66% ‘unavoidable’. Route to diagnosis varied by diagnostic group. All malignant melanoma patients were referred via 2WW, compared to very few of the bone sarcoma or brain tumour patients.

Key event interval analysis
The longest median diagnostic interval (from first presentation relating to the cancer diagnosis to date of diagnosis) was observed in bone sarcoma patients (81 days, range 24 - 140 days). The shortest diagnostic intervals were observed in leukaemia patients, followed by germ cell tumour patients.

Clinical bottom line
Of the 98 evaluable pathways, 40% were deemed to represent good or best practice. 44% of pathways were evaluated as requiring room for improvement, 16% of pathways were considered less than satisfactory. This varied between diagnostic groups. All bone tumour pathways were deemed either room for improvement (29%) or less than satisfactory (71%). Of the lymphoma pathways evaluated, 65% were room for improvement and 12% less than satisfactory. In comparison, 78% of leukaemia pathways were deemed to represent good practice followed by 67% of germ cell tumour pathways.

Impact and Benefits
Emerging themes for areas of improvement have been identified including:

- Accountability for/effective management of patients within secondary care pathways
- Radiology reporting and response to positive investigations
- Application of NICE referral guidance in TYA
- Patient experience and role of a debriefing exercise and early re-engagement with primary care

Outcome
The findings will be used to recommend and implement specific local interventions. This will follow further planned interrogation of secondary care pathways e.g. the lymphoma pathway. A project involving early re-engagement with primary care is in the pilot phase.
A70 Manchester Cancer Jaundice Pathway

Overview

The Manchester Cancer (MC) Jaundice Pathway sits within the HPB (hepato-Pancreato-Biliary) Pathway board’s strategy for improving outcomes in HPB cancer. The MC Jaundice Pathway provides for earlier diagnosis of pancreatic cancer as well as timely referral and improved pathways.

Context

Pancreatic cancer has the lowest five year survival of any cancer in Europe. Most patients present with jaundice. Some of the reasons for such poor outcomes are delays in diagnosis and treatment. We believe that pancreatic cancer should be treated as an oncological emergency.

The problems with the existing system are threefold: lack of timeliness, poor patient experience and high complications rates. A baseline audit of timeliness was undertaken. Among 422 patients with pancreatic cancer presenting to the HPB unit at North Manchester General Hospital between July 2007 and March 2014, time from ultrasound (USS) or computed tomography (CT) to further investigation or treatment was as follows:

- USS to CT time 7 days (median) range (1-156)
- USS to endoscopic retrograde cholangiography (ERCP) time 10 days (median) range (1-189)
- USS to operation time 57 days (median) range (4-156)
- CT scan to surgery median time 33 days (range 1 – 153)

Aim and Objectives

The aim of the Manchester Cancer Jaundice Pathway is to provide for earlier diagnosis as well as timely referral and improved pathways.

Description of new pathway or service

The key innovations are twofold:

1. Same day definitive radiological imaging for patients presenting with obstructive jaundice not due to gallstones. The purpose is to provide for earlier diagnosis and timely referral and to improve patient experience.

2. Fast-track referral for jaundiced patients with pancreatic cancer for early surgery. The aim is to reduce overall complications and prolong survival.
Results

1. One-stop clinics

One-stop jaundice clinics based on the Manchester Cancer Jaundice Pathway template have been established in Macclesfield Hospital, Pennine Acute Trust (PAT) and Central Manchester Foundation Trust (CMFT).

Data from the pilot site at Macclesfield Hospital: There were 28 patients referred over 18 months starting Dec 2015; age 36 to 89 years and the average age was 69.5. The M:F ratio was 1.3:1. 16/28 patients were discussed at HPB MDT; 12 had clinic follow up. 100% had investigation /GI review within two weeks; 96% had outcomes within two weeks. The majority of cancers diagnosed were upper-GI tract malignancies including pancreatic cancers as well as lung and lower GI. Other diseases diagnosed included gall stone disease, chronic liver disease and hepatitis.

Data from other sites: The one-stop jaundice clinic at PAT commenced on 8th March 2016. Of the first nine clinic patients seen, the average age was of 70 years and an M:F ratio of 1.6:1. The mean waiting time between GP referral to clinic was 5.5 days (range 1-7 days). All had relevant imaging on the same day.

The overall cancer pick-up rate for these clinics was 24% (9/37).
2. Fast track surgery

Between 1st of January 2016 and 1st of October 2016, there were 31 referrals for fast track (same week) pancreatic surgery of which 15 proceeded. Reasons for not proceeding to surgery were as follows:

- Stone disease
- Bilirubin excessively elevated (>250)
- Comorbidity preventing fast track
- Uncertainty of diagnosis
- Advanced disease
- Psychological well being
- Failed to follow pathway

Outcomes for those who proceeded to surgery demonstrated quick times from presentation, ultrasound and CT to surgery (table 1). A comparison of median times from diagnostic investigation to surgery demonstrates that this has improved when comparing data from the pre-implementation audit to that post implementation. Time from ultrasound and CT scan to surgery has decreased from a median of 57 and 33 days pre-pathway to 13 and nine days respectively post pathway.

<table>
<thead>
<tr>
<th>Patient (N=15)</th>
<th>Median</th>
<th>Range</th>
<th>Pre-Pathway median</th>
<th>Pre-Pathway range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time from presentation to surgery</td>
<td>14</td>
<td>8-50</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(days)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bilirubin at time of referral</td>
<td>147</td>
<td>57-219</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(µmol/L)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interval time from USS to surgery</td>
<td>13</td>
<td>3-41</td>
<td>57</td>
<td>4-156</td>
</tr>
<tr>
<td>(days)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interval time - CT to surgery</td>
<td>9</td>
<td>3-40</td>
<td>33</td>
<td>1-153</td>
</tr>
<tr>
<td>(days)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bilirubin at time of surgery</td>
<td>189</td>
<td>50-310</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(µmol/L)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time from referral to surgery</td>
<td>5</td>
<td>1-13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(days)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Post op length of stay</td>
<td>11.5</td>
<td>7-61</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(days)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 1: Interval time between presentation, ultrasound and surgery

Impact and Benefits

The Manchester Cancer HPB Board has identified that reducing delays in the diagnosis and treatment of patients with pancreatic cancer presenting with jaundice represents our best chance of improving outcomes in this disease.

One-stop jaundice clinics deliver same day imaging, have a high cancer pick up rate (24%) and facilitate timely diagnosis and treatment. Fast track surgery for pancreatic cancer is feasible and safe and greatly reduces time to treatment.
| **Outcome** |
|-------------|---|
| Manchester Cancer Jaundice Pathway templates have been established in Macclesfield Hospital, Pennine Acute Trust and Central Manchester Foundation Trust. Anticipated sites opening similar one stop jaundice clinics in 2016 are Stepping Hill Hospital and Salford Royal Infirmary. The project is seeking long term funding from the GM heads of commissioning to ensure the continuation of the service which is supported by the Manchester Cancer Provider Board. |
A81 Suffolk Unintentional Weight Loss Pathway

Overview
The project implemented and evaluated two unexplained weight loss pathways for the early diagnosis of cancer and other conditions.

Context
- Weight loss is a near universal feature of illness, with a varied and complex mechanism characterised by decreased energy input, excess energy expenditure and energy loss
- Unexplained weight loss can be an early predictor for a wide range of conditions, including mental health conditions, and is in itself a predictor for increased risk of morbidity and mortality
- NICE-suspected cancer: recognition and referral (2015) suggest that weight loss patients should be offered investigations within two weeks as it can be an early sign of some cancers, including lung cancer and colorectal cancer

Aim and Objectives
- To implement and evaluate an unexplained weight loss pathway
- To determine if referral of patients with unexplained weight loss to the pathway leads to timely diagnosis and intervention

Description of new pathway or service
A simple pathway was devised to offer rapid clinic OPA within two weeks for patients with weight loss > 5%, having undergone simple triage tests in primary care including chest-x-ray and abdominal ultrasound to identify possible causes for the weight loss. If these were negative or inconclusive the patient was referred rapidly to a specific unexplained weight loss clinic. Two pathways were set-up in East and West Suffolk led by gastroenterologists.
Results

**East Suffolk**
- Pilot study January 8th 2014 – November 30th 2014
- No. of patients: 54

Five (9%) cases of cancer were diagnosed (lung cancer, colon cancer and haematological cancer) and were referred to the appropriate specialties (respiratory, colorectal and haematology). Other causes and diseases were identified cholecystitis, GI disease, neurological, cardiorespiratory, a side effect of a diabetes related drug, and other co-morbidities – no causes were found in 12 cases and less than five declined or didn’t attend.

**West Suffolk NHS Foundation Trust**
- Pilot study 1st October 2014 – 1st October 2015
- No. of patients: 32
- Age 19-91 with a mean age of 68 years old
- M:F ratio was 1:1.4
- Mean duration of weight loss was 11.5 months
- 29 had regained weight at the time of out-patient appointment
- Follow up project 1st October 2015 to September 2016
- No. of patients: 91
- Age 18-91 with a mean age of 64 years old
- M:F ratio was 1:1
- Mean duration of weight loss was 32 weeks
- 27 had regained weight at the time of out-patient appointment

**Taking into account the result of the pilot and the follow up project:**
Of the 123 patients referred, eight (6.5%) patients were diagnosed with cancer (head and neck, haematological, pancreatic and lung cancer). Of those less than five had previous malignancies or metastases. Less than five were early stage with good prognosis.

Other causes of weight loss in patients were:
- 22 neuropsychiatric illness
- 11 inflammatory bowel syndrome
- 5 inflammatory bowel disease
- 8 chronic respiratory causes
- 11 gastrointestinal-related diseases included coeliac disease, diverticulitis, campylobacter infection, gastritis, dysphagia, small bowel obstruction
- 9 others (post-operative weight loss, heart failure, side effect of treatment, nasal polyp, eating disorder)
- 27 regained weight lost due to an acute illness or nutritional cause
- 12 no cause found but weight stabilised or regained subsequently
- 10 still under investigation

**Impact and benefits**

The pathway indicated that weight loss can be an indicator for a wide range of illnesses, including cancer. The conversion rate to cancer was 6.5%.

**Outcome**

Suffolk is considering expanding the symptom base to include a broader range of non-specific symptoms and developing multi-disciplinary diagnostic centre(s).
Overview

The aim of the project was to improve earlier cancer diagnosis through refined referral criteria for patients who present with non-alarm symptoms (vague) including the prioritisation of cancer types that would benefit from GP direct access to diagnostics. The intention was that this would then lead to improved overall Slough cancer diagnostic rates, reduced emergency cancer presentations and improve the overall quality of referrals into secondary care.

Context

The National Cancer Intelligence Network (NCIN) benchmarking data showed that 5.7% of Slough GP 2WW referrals deliver a diagnosis of cancer, compared with the national average of over 10%. In response to this Slough CCG decided to investigate referral rates into Frimley Health, Heatherwood and Wexham Park Hospital (HWPH) by specialism and found significant variations in volume by Slough practices. Based on this evidence, it was proposed that Slough CCG and Frimley Health Wexham Park Hospital collaboratively prioritise four clinical areas (gynaecology, urology, general surgery, and tumours of unknown primary) in which to observe patient journey to identify areas for improvement.

Aim and Objectives

- To identify evidence of need for GP direct access to diagnostics
- To refine/develop local referral criteria for patients who present with vague symptoms
  - Routine referrals
  - Direct access to diagnostics
- Frimley Health require the identification of pathway improvement areas, for service development

Description of audit

The Primary Care Cancer Audit covered the analysis of the overall patient journey from pre-referral, referral investigations, diagnosis through to treatment outcomes, looking at timelines between key care episodes compared against cancer stage at diagnosis.

The slide below shows the specialist areas that formed part of the audit:
### Results

A thematic analysis of the results (37 patient case files) has taken place. Some common general themes have emerged, but none specific to a type of cancer.

1. GPs have fed back that patients lack awareness of potential cancer symptoms. If patient knowledge could be increased and patients visit GPs more quickly, earlier diagnosis would be possible.
2. GP education and awareness of cancer symptoms, including vague symptoms needs to be repeated, via educational afternoons and cancer master classes – the audit results suggest that GPs are making routine referrals when some patients should have been referred under a 2WW.
3. There is no advice and guidance available for GPs for discussing cases where they are unsure – East Berks to learn from other areas in ACE project where services have been implemented.
4. A named cancer lead in each practice could help to formalise learning available from the voluntary sector and aid discussion and help between peers in practice.

### Impact and Benefits

The findings for this work have been included in the development of a Cancer Local Action Plan for Berkshire East. The implementation project is in “start-up” and has included the four emerging themes within the scope of the prevention and early diagnosis work stream. The work stream is led by the Berkshire East clinical lead for cancer.

### Outcome

The following will be included in the scope of the prevention and early diagnosis work stream of the Cancer Local Action Plan implementation project:

1. Working with public health to support existing campaigns for public awareness of symptoms
2. Request for each practice to nominate a cancer champion
3. A series of masterclasses lead by the Berkshire East cancer lead will update GPs on key findings for men’s, women’s and children’s cancers
4. Targeting of identified practices for additional third sector support in relation to best practice in screening work, 2WWs and safety netting
5. Review of potential for a GP support line to both radiologists and oncologists to increase appropriateness of referrals