Improving diagnostic pathways for patients with vague symptoms

Executive summary

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 Pathway Cluster
April 2017

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 from March 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.

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 that are currently not served well by existing processes and pathways 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 referral or is unsure of the primary cancer site

Purpose

The aim of the projects was to monitor and evaluate the 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 vague but serious symptoms.

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

- **Intervention based studies** – where a new service or pathway has been 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.

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_ [1] (Independent Cancer Taskforce, 2015).

Some cancers can be more difficult to diagnose, in particular those that present with vague symptoms. 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 [2] (McPhail S, 2015), as well as a poor experience for the patient [3] (Mendonca SC, 2016).

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 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 [4] (National Institute for Health and Care Excellence, 2015).

Findings

1) **Time to Diagnosis:** The time to diagnosis can be improved for patients with non-specific and 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 two week wait 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 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) following normal chest x-ray. 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 chest x-ray [5] (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) **Cost-effectiveness:** The projects reported here did not directly measure costs. However, innovations to reduce unnecessary appointments or diagnostic tests should theoretically lower costs. The faster diagnostic pathways and high conversion rates to cancer demonstrated by some projects could be indicative of the efficient use of resources by getting patients to the right test at the right time, and by avoiding presentation at Accident and Emergency.

6) **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 two week wait 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 multi-disciplinary diagnostic centre 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.

References

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5) National Lung Screening Trial Research Team, C. T. (2013). Results of initial low-dose computed tomographic screen. *N Engl J Med 368(21)*, 1980-91 .