Realist Evaluation of the ACE Programme
2015-16

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Executive Summary

Background

The ACE (Accelerate, Co-ordinate, Evaluate) programme was developed by NHS England, in partnership with Cancer Research UK and Macmillan Cancer Support, in order to accelerate the pace of change towards earlier cancer diagnosis by extending the range of diagnostic pathways available. Its overarching aim is to develop a national body of evidence and evaluation that informs the operational improvement of early diagnosis cancer pathways through the 2016/17 and 17/18 commissioning rounds. Following a national call for expressions of interest in June 2014, 60 projects were selected, organised into eight themes or clusters. The Policy Research Unit for Cancer Screening, Awareness and Early Diagnosis was asked to undertake an evaluation of the programme. Within that commission, the Evaluation, Research and Development Unit at Durham University undertook a qualitative evaluation of its implementation at selected sites.

Methods

We undertook detailed case studies at nine of the 60 sites, selected purposefully in consultation with the ACE programme director and Cluster leads. Data were generated from sequential one-to-one interviews, review of meeting notes and observation of cluster action learning sets. Interviews were recorded, transcribed and analysed using a Framework approach. We used a method of realistic evaluation to explore ‘what worked for whom and in what circumstances’. We also used Normalisation Process Theory where appropriate to understand the extent to which projects were successfully implemented.

Results

Between March 2015 and September 2016 we conducted 142 interviews across nine sites, distributed between four of the eight clusters. The most important contexts identified were the prevailing organisational culture and the presence of those factors known to be associated with successful quality improvement. Being part of a
high profile, national initiative was also important. The mechanisms that emerged as enabling implementation included good quality project management, clinical leadership and engagement and communication within and between partner organisations. The extent to which these were present varied considerably. We assessed eight of the nine projects studied as being successfully implemented. The extent to which each had become normalised, or incorporated into the working practice of users and providers, was variable. Some of the outcomes identified by project teams at the outset were amenable to hard quantitative measures and will be the subject of the parallel PRU quantitative evaluation. Others were less clearly specified, though there was limited and anecdotal evidence that they had been achieved in some instances.

Conclusions

Participants in the ACE programme were in general highly motivated to drive forward their plans for service improvement. In most of the projects that we studied they proved successful in doing this. However it was apparent that a more critical assessment of the shared understanding and commitment within and between organisations, and of the capacity, capability and skills required for the project, would have benefited some. In any future ‘mainstreaming’ of service improvements in cancer diagnostics, appraisal at the planning stage against the success criteria we have identified could help ensure that the key elements are in place for successful implementation.
1.0 Background and Introduction

The English National Awareness and Early Diagnosis Initiative (NAEDI) (Richards, 2009) was launched in 2008, in response to the Cancer Reform Strategy (Department of Health, 2007), in order to understand and address the reasons for late diagnosis of cancer in England.

Early NAEDI initiatives included a programme of media campaigns aimed at raising public awareness (Be Clear on Cancer), a National Audit of Cancer Diagnosis (Rubin et al, 2011), and guidance for GPs intended to promote greater use of diagnostic tests for cancer Following the publication of Improving Outcomes: a Strategy for Cancer (Department of Health, 2011), there was an increased emphasis on diagnostic testing for GPs, with additional funding to PCTs to enable this. The ACE programme (Acceleration, Coordination and Evaluation) responded to a desire to accelerate the pace of change towards earlier diagnosis by extending the range of pathways to cancer diagnosis. It was informed in part by developments in cancer diagnostic services in other countries, notably in Denmark (Vedsted & Oleson, 2015). The ACE programme was initiated in June 2014 as a set of projects that would explore specific interventions and models, with the aim of ‘preventing people from dying prematurely’. It is supported by NHS England, Cancer Research UK (CRUK) and Macmillan Cancer Support and was planned to run in 2015 and 2016.

The overarching objective of the ACE programme is to develop a national body of evidence and evaluation that informs the operational improvement of early diagnosis cancer pathways through the 2016/17 and 17/18 commissioning rounds.

A launch event was held in June 2014 and expressions of interest sought for projects to be included in the ACE programme. Sixty projects were identified and then organised into eight groups or “clusters”:

- Lung Cancer Pathway – considers effective and efficient pathways from referral and diagnosis
• Proactive Approach to Patients at High Risk of Lung Cancer – considers effective methods of case finding of people with high risk of developing lung cancer.

• Colorectal Cancer Pathway – considers straight to test, best first test, and referral thresholds for colorectal cancer pathways.

• Bowel Screening Uptake – considers interventions to increase screening uptake in different target groups.

• Cancer Screening Uptake for Vulnerable Groups – considers ways to remove barriers to screening for vulnerable groups including learning difficulties, sensory impairment and minority ethnic groups.

• Vague Symptoms Pathway – considers approaches for patients that present with vague symptoms that may not fit into current 2 Week Wait (2WW) pathways.

• Pharmacy & other Primary Care – considers enhanced roles for primary care professionals other than GPs to identify referral of patients with suspected cancer.

• IT Tools – considers the use of cancer decision support tools to identify high risk patients.

The Policy Research Unit (PRU) for Cancer Awareness, Screening and Early Diagnosis was commissioned to evaluate the ACE programme. Within that commission, the Evaluation, Research and Development Unit (ERDU) at the University of Durham was asked to undertake a qualitative evaluation of the implementation of the programme in selected sites.

Nine projects from four clusters (Colorectal cancer pathways, Proactive approach to patients with a high risk of lung cancer, cancer screening uptake for vulnerable groups and vague symptoms pathway) were chosen for evaluation. These projects were purposively selected in consultation with the ACE Programme Director and Cluster Leads.
This report describes the development and implementation process for the selected projects by considering the contexts, mechanisms and outcomes that operated at each of the nine projects. The overarching themes that were common to all the projects are considered in the main text, but each of the nine projects is the subject of a detailed case study and these are provided as appendices.
2.0 Methods

2.1 Realist Evaluation

We used the method of realistic evaluation (Pawson and Tilley 1997). This theory-driven approach explores the relationship between the outcomes (intended and unintended consequences), mechanisms and contexts of a programme by mapping out and then testing the ‘programme theory’. A realistic approach helps to illuminate if and why certain elements of the ACE initiative resulted in particular outcomes. It helps the commissioner of the research to understand ‘what worked for whom and in what circumstances’ and is increasingly being recognised as a valuable approach to understanding how particular preconditions make intended outcomes more or less likely.

The evaluation was based on nine detailed case studies. These were purposefully selected in consultation with the ACE Programme Director and Cluster Leads to understand in greater depth a range of approaches to the implementation of the ACE programme.

The criteria for selection of case studies included:

a. The cluster at which the interventions were being directed (e.g. screening for vulnerable groups, vague symptoms colorectal etc)
b. The type of intervention being implemented
c. The stage of development of the intervention

The case studies contained the following components:

a. An exploration of the mechanisms that each area had put in place through the ACE programme to develop an understanding of the context in which these mechanisms have been put in place, through one to one interviews with clinicians, managers, commissioners and other key informants in each area.
b. Review of notes from action learning sets, meeting notes, activity logs and other material

c. Attendance at cluster action learning sets to develop a greater understanding of the contexts, mechanisms and outcomes related to the cluster and individual interventions

We used sequential one to one interviews with clinicians, managers, commissioners and other key informants in each project. Potential participants for interviews were identified by the local project lead.

Information sheets and consent forms were emailed to potential participants. They were asked to complete the consent form and return it if they were willing to participate. A convenient interview time was then arranged. Consent was re-confirmed verbally before each interview began.

It was anticipated that participants would each be interviewed up to three times, once early in the implementation stage, once mid-point and finally towards the end of the project.

Interviews lasted approximately one hour and were either face to face or via the telephone. The number of interviews per project site differed depending upon the number of key stakeholders per intervention. The first round of interviews were carried out in March–July 2015, with the second round of interviews conducted between October 2015 – February 2016 and final interviews in March – September 2016.

All project sites were visited. In the first round, a total of 46 1:1 interviews were conducted. At each site between three and nine key informants were interviewed. They came from a range of professional backgrounds and included GP Leads, Project Managers, Programme Leads, Public Health specialists, Secondary Care clinicians and managers, Commissioning leads and managers, and other clinical and non-clinical staff. Each interview took approximately one hour. In the second round 49 1:1 interviews were carried out. In this round of interviews there were a number of new informants who had not been interviewed initially, they were introduced due to the
fact they had either not been in post at the initial interviews or their role had not been as significant in the initial stages of the project. There were also a small number of informants who declined to participate in the second round of interviews as they felt they had nothing new to contribute. In the final round, 47 1:1 interviews were conducted. Again some informants felt they had nothing new to contribute so declined the offer of a final interview. There was one new post holder and one additional person whose overall reflections of the project were thought to be relevant.

Table 1 Number of interviews for each case study

<table>
<thead>
<tr>
<th>Cluster/Locations</th>
<th>Interview Round</th>
<th></th>
<th></th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Colorectal Pathway</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>- Croydon Health Services NHS Trust and Croydon CCG</td>
<td>9</td>
<td>7</td>
<td>5</td>
<td>22</td>
</tr>
<tr>
<td>Colorectal Pathway</td>
<td>4</td>
<td>4</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>- Whittington, Wigan and Leigh NHS Foundation Trust</td>
<td>7</td>
<td>8</td>
<td>8</td>
<td>23</td>
</tr>
<tr>
<td>Proactive Approach to Patients at High Risk of Lung Cancer</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>12</td>
</tr>
<tr>
<td>- Liverpool Health Lung Project</td>
<td>5</td>
<td>4</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td>Vague Symptoms Pathway</td>
<td>5</td>
<td>6</td>
<td>6</td>
<td>17</td>
</tr>
<tr>
<td>- Airedale, Wharfedale and Craven CCG and Airedale NHS Foundation Trust</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Vague Symptoms Pathway</td>
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<tr>
<td>- Chesterfield Royal Hospital NHS Foundation Trust</td>
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<tr>
<td>Vague Symptoms Pathway</td>
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<td></td>
<td></td>
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<tr>
<td>London Cancer Alliance</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>- University College London Hospitals NHS Foundation Trust (UCLH)</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Vague Symptoms Pathway</td>
<td>London Cancer Alliance - Queens Hospital</td>
<td>3</td>
<td>5</td>
<td>3</td>
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<tr>
<td>------------------------</td>
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</tr>
<tr>
<td>Screening Uptake for Vulnerable Groups - Blackburn with Darwen and East Lancashire CCGs</td>
<td>4</td>
<td>6</td>
<td>5</td>
<td>15</td>
</tr>
<tr>
<td>Screening Uptake for Vulnerable Groups - North East and Cumbria Learning Disability Networks</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>18</td>
</tr>
</tbody>
</table>

Interviews were recorded and fully transcribed, and analysed using a Framework Analysis approach. Framework analysis is an approach to analysis developed for applied policy research, which allows the exploration of issues of interest as well as allowing for new issues to emerge (Ritchie and Lewis, 2003). Transcripts were read by two members of the research team in order to identify themes and construct a framework; the framework was then applied to all transcripts systematically. The team then reviewed the transcripts and themes to ensure consistency and agreement of interpretation.

In addition to the interviews, documentary evidence relating to the projects such as project plan, notes and strategies were also reviewed. Attendance by the researchers at ACE Cluster Group meetings along with other material such as meeting notes, local activity data and other documents relating to the projects provided by the sites was valuable in helping the researchers gain a deeper understanding of the contexts, mechanisms and outcomes relating to the whole cluster and also to individual projects within the cluster.

Once the individual case studies were complete, each project team was sent a copy of their case study to review for factual accuracy.
2.2 Normalisation Process Theory

For projects that were intended to become mainstream services, Normalisation Process Theory was used to understand the extent to which projects were successfully implemented and became embedded into routine practices.

Normalisation process theory (NPT) is a sociological theory of the implementation and integration of new technologies and organisational innovations. It proposes that practices become routinely embedded in social contexts as the result of people working, individually and collectively to implement them. It enables us to understand how an intervention, whether it is a technology, procedure or pathway, becomes a routine part of normal practice within a social context (May, 2006)(May and Finch 2009).

A number of the organisational innovations in this evaluation were amenable to analysis using NPT. Innovations may be normalised, i.e. become custom and practice, but other outcomes are possible. They may become adopted, that is accepted and taken up but not embedded into routine practice, or they may be rejected, where interventions are disregarded or used in a way that subverts the initial purpose of the intervention (May, Finch, Mair et al., 2007).

To understand the embedding of a practice it is necessary to consider what people actually do and how they work. In this context the theory proposes that the work of implementation is operationalised through four generative mechanisms (coherence, cognitive participation, cognitive action, reflexive monitoring). These are affected by factors that promote or inhibit the routine embedding or normalisation of a practice in its social contexts. They form the basis of a framework proposed by May and Finch as a means of applying normalisation process theory, and used by us for that purpose (table 2).
Table 2 - Framework for operationalising normalisation process theory

<table>
<thead>
<tr>
<th>Coherence</th>
<th>Cognitive participation. Who does the work?</th>
<th>Collective action</th>
<th>Reflexive monitoring</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What is the work?</strong></td>
<td><strong>Factors that promote or inhibit the mobilisation of a practice</strong></td>
<td><strong>Factors that promote or inhibit participation in a practice</strong></td>
<td><strong>Factors that promote or inhibit the appraisal of a practice</strong></td>
</tr>
<tr>
<td><strong>Who does the work?</strong></td>
<td><strong>Beliefs and behaviours that define and organise objects</strong></td>
<td><strong>Beliefs and behaviours that define and organise actors</strong></td>
<td><strong>Beliefs and behaviours that define and organise understanding</strong></td>
</tr>
<tr>
<td><strong>How does the work get done?</strong></td>
<td><strong>How is a practice conceptualised by participants? How does it hold together in action?</strong></td>
<td><strong>How do participants come to engage with a practice? How do they decide on engagement and the purposes that it serves?</strong></td>
<td><strong>How do participants appraise a practice? What are its effects of appraisal? How are they mediated?</strong></td>
</tr>
<tr>
<td><strong>How is the work understood?</strong></td>
<td><strong>Factors that promote or inhibit mobilisation of a practice</strong></td>
<td><strong>Factors that promote or inhibit participation in a practice</strong></td>
<td><strong>Factors that promote or inhibit the appraisal of a practice</strong></td>
</tr>
<tr>
<td><strong>Systematic explanation of mechanisms and components at work</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Knowledge about the sources and operation of investments at work</strong></td>
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</tr>
<tr>
<td><strong>Investigation of core questions that could include . . . . .</strong></td>
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</tbody>
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3.0 Overarching Themes

3.1 ACE Programme

The overarching objective of the ACE programme was to develop a national body of evidence and evaluation that informed the operational improvement of early diagnosis cancer pathways through the 2016/17 and 17/18 commissioning rounds.

The core programme team was recruited and hosted by Cancer Research UK (CRUK) and expressions of interest were invited from the NHS community. These were subsequently validated via a series of phone calls with submitting organisations and those thought to be viable were categorised into eight clusters:

- Lung cancer pathway
- Vague symptoms pathway
- Colorectal pathway
- Bowel screening uptake
- Proactive approach to patients at high risk of lung cancer
- Screening uptake for vulnerable groups
- Pharmacy/other primary care
- IT Tools/eCDS

Proposals for local improvement submitted for inclusion in the ACE programme embraced a range of interventions across the country. Each intervention was specific to the needs and priorities of its locality. While all had the overall aim of improving cancer diagnosis and ultimately survival, there were differences in the mechanisms used to drive changes in services and the contexts within which these mechanisms were implemented.

As part of the qualitative evaluation nine sites were selected from the 60 sites included in the ACE programme for review and case studies developed. The sites were chosen in conjunction with the ACE Cluster Leads and the criteria for selection included the type of intervention being implemented and the stage of development of that intervention. The selected sites came from the following four clusters:
• Vague symptoms pathway – four sites
• Colorectal pathway – two sites
• Proactive approach to patients at high risk of lung cancer – one site
• Screening uptake for vulnerable groups – two sites

The underlying programme theory for ACE was that projects already formulated or in development would be enabled to be successfully implemented by being part of a national programme (ACE) that provided support, funding and opportunities for shared learning.

By the end of the evaluation period, eight of the nine case study projects (see Appendices D-E for details of the projects) had been successfully implemented, although they were at different stages of becoming fully incorporated into the working practices of clinicians and organisations (see the methods section 2.2 of this report for further details about Normalisation Process Theory).

Analysis of the interviews resulted in the development of a Contexts, Mechanisms, Outcomes (CMO) model for each project (see appendices B-E). The programme theory for each individual project differed and each CMO configuration was refined as the interviews progressed to produce the final CMO model for that case-study.

In figure 1 we give the CMO model for the ACE programme as a whole, with its overarching contexts, mechanisms and outcomes.
3.2 Key Context Mechanisms and Outcomes (CMO)

We identified a number of themes that were common to the majority of projects. These are discussed below:

3.2.1 Contexts

3.2.1.1 ACE Programme (C1)

Being part of the overarching ACE programme was cited as an important context in interviews at all sites, even though, in every case study, interviewees felt that their project would have happened without ACE. The possible exception is the two London Cancer sites, as they were initially approached by London Cancer to participate in the programme and did not initially generate the idea for their project themselves.

Being part of the ACE programme brought a range of perceived benefits including additional finance, but also credibility for the project within the host organisation because it was a national initiative with evaluation seen as an integral part and an opportunity to share and learn from others:
“The money we got from ACE certainly helped as it enabled us to appoint some-one to devote their time to the project management and ensure the project stayed on track, I think we would have struggled without that resource”

Macmillan GP

“I think being involved in ACE was beneficial as it helped internally keep people focused, knowing that there is external scrutiny sometimes helps and raises the profile of something within the organisation”

Project Manager

“Yes, the cluster groups were useful as a forum to discuss what other people were doing and learn from them, it’s really useful to share experiences, and the support we had from the Cluster programme lead was good too”

Service Improvement Manager for Cancer Services

3.2.1.2 Organisational culture (C2)

Organisational culture varied between projects. Some organisations were able to describe a long history of service improvement at this scale, with a proactive approach to developing services and change management. For others the scale of the required change and the number of organisational boundaries that needed to be crossed presented new and different challenges. A few projects were hosted by organisations where the prevailing culture was reactive rather than proactive and interviewees reported that staff spent a significant amount of time managing problems rather than developing or refining services:

“So, they already had done a lot of cancer pathway redesign work and were very used to doing that sort of work, the organisation is committed to improving services for these people, so it was pushing against an open door really”

Project Manager

“I think the real challenge has been dealing with all the different organisations, whose cultures are different, whose views are different, they operate differently, sometime even the language is different and you need to be quite skilled to manage
the associated sensitivities and understand how to tap into each organisation to get the best out of them”

Macmillan GP

“Unfortunately the culture of the organisation is one where firefighting is at the fore, you know there are so many day to day issues that need resolving just to keep everything functioning they focus on that and there is no real desire to focus on anything new that might bring different problems to those they are already dealing with”

Project Manager

Organisations where staff felt stable and secure in their roles appeared to be more effective at implementing change, whilst those undergoing structural change, where roles where changing and people had to compete for their own jobs, were less likely to be able to implement change effectively.

3.2.1.3 National and local agenda (C3)

All the case studies reflected aspects of the national cancer agenda, by aiming to promote earlier diagnosis, develop new pathways or seeking to increase screening uptake. In addition, the projects implemented in all these case studies were all driven by an identified local need and the solutions to addressing that need were developed locally whilst linking in with national programmes:

“We identified the problem a few years ago and wanted to do something about it, but the time just wasn’t right from an organisational perspective and I had colleagues who were resisting the proposed change so we had to put it on hold . . . . . . By the time the call for ACE projects came things had changed so we relooked at it and decided to implement it locally with the support from ACE”

Lead Clinician

“We’ve developed the pathways with a very local focus, but we are always interested in what is going on nationally, how that might affect or influence us and how we might contribute to national learning”

Macmillan GP
All projects shared the aspiration of the ACE programme to develop the national evidence base.

3.2.1.4 Commitment to quality improvement (C4)

All the case studies where projects were successfully implemented were able to describe a commitment to quality improvement. The range of commitment differed between projects, for example, some projects had one or two individuals who were very passionate and committed to quality improvement and who proactively led their projects. Other projects where much more structured and organised in their approach to quality improvement, putting structures and processes in place to ensure delivery of the project. These projects also described more shared ownership and responsibility for quality improvement:

“The service is there because of DD, without his commitment, hard work and leadership it simply would not have happened, really it’s all been done on his goodwill”

Lead GP

“We are all committed to the project, and feel it’s a really important piece of work. The way we’ve managed the project with the work streams, has gone well, we (steering group members) lead work streams where we have the most expertise so we really do understand the issues faced by our work stream. We then feedback progress and issues to the steering group, this approach really does work very well indeed”

Macmillan GP

3.2.2 Mechanisms

3.2.2.1 Project management (Ma)

Project management is the application of processes, methods, knowledge, skills and expertise to achieve defined objectives, which may be outputs, outcomes or benefits. The core components of project management include project definition, management planning and progress monitoring, resource allocation and management, risk management and communication
Effective project management was an important mechanism in all of the projects, though the model of project management differed amongst sites. At three, Liverpool, Croydon Health Services NHS Trust and the North East and Cumbria Learning Disability Network, there were designated full time project managers funded by ACE. Two sites, Queens Hospital, Romford and UCLH, were jointly supported by the London Cancer Quality Manager, who provided project management for them. The remaining four sites, Wrightington, Wigan and Leigh NHS Trust, Blackburn with Darwen and East Lancashire CCGs, Airedale, Wharfedale and Craven CCG and Airedale NHS Foundation Trust and Chesterfield Royal Hospital NHS Foundation Trust, had one or more individuals who provided a project management function which was additional to their substantive role responsibilities. Whilst all projects demonstrated elements of the core components described above, only one project (Liverpool) described using a formal project management model (PRINCE2) to assist them.

3.2.2.2 Leadership (Mb)

Leadership in this context refers to leading a group of people to facilitate change in practice as part of the ACE programme. Leadership came from a variety of sources including GP Leads, Secondary Care Clinical and Managerial Leads, Commissioners and Project Managers.

All of the successful projects had at least one clearly identifiable person who had a clear vision and communicated it in an articulate manner, though the style of leadership differed between projects. A transformational style of leadership was the one observed to be most prevalent by interviewees, i.e. one focused on implementing change that inspires others to follow a clear vision.

Interviewees in the case study where the project was not successfully implemented (Queens Hospital, Romford) described a different style of leadership, transactional leadership, which is based on transactions or exchanges between the leader and the follower. This style of leadership works best when tasks are simple and those
required to undertake those tasks are subordinate to the leader. It was unsuited to a situation where those being led were other professionals and the task was complex.

3.2.2.3 Evaluation of resources (Mc)

Every project described capacity as a potential or real pressure which materialised as the project developed. Many expressed concern about whether they could meet demand for additional diagnostic capacity such as radiology or endoscopy; these included Croydon Health Services, NHS Trust and Wrightington, and Wigan and Leigh NHS Trust. Other projects, such as the North East and Cumbria Learning Disability Network, Blackburn with Darwen and East Lancashire CCGs, Queens Hospital, Romford and Chesterfield Royal Hospital NHS Trust, were concerned that clinicians (doctors and nurses) might not have sufficient time to deal with the additional activity generated by the project. In addition, a number of projects expressed a view that without the resource of a dedicated project manager they would have been unlikely to implement the project or at the very least put plans in place to deal with some of the practical issues arising from implementation. These included Liverpool and the North East and Cumbria Learning Disability Network. Some projects such as Liverpool and UCLH considered all of the above scenarios.

Some projects, such as Liverpool and Wrightington, Wigan and Leigh NHS Trust, did some capacity modelling to identify required radiology or endoscopy capacity; others such as Croydon Health Services NHS Trust only identified lack of capacity as a problem when demand i.e. the numbers of patients requiring diagnostic tests started to increase beyond their initial capacity. When a shortage of endoscopy capacity emerged in Croydon Health Services NHS Trust and at Wrightington, Wigan and Leigh NHS Trust, the project teams sought to create additional ad hoc capacity by getting clinicians to do additional endoscopy lists or to work on evenings or weekends.

Radiology capacity was specifically considered at Airedale, Wharfedale and Craven CCG and Airedale NHS Foundation Trust and Liverpool. Demand did not exceed capacity in Airedale, Wharfedale and Craven CCG and Airedale NHS Foundation Trust.
but in Liverpool one site reported a backlog of scans requiring reporting. This was resolved by radiologists from another Trust providing their time to clear the backlog.

Clinicians’ time to meet additional patient demand was generally dealt with by reviewing and changing job plans or roles prior to project implementation.

3.2.2.4 Connections and Communications between clinical staff, patients and other stakeholders (Md)

All the projects that were successfully implemented identified the need to communicate with clinical staff and other stakeholders and this was done in a variety of ways, ranging from one to one discussions to regular steering group meetings, with most projects opting for a steering group to be the focal point for communication with stakeholders. Successful communication was based on all parties understanding the project and their specific role within it. One project (Liverpool) developed a communication plan prior to implementation of the project; other projects identified communication strategies such as emails and newsletters to GPs, newsletters within secondary care and education events that highlighted the purpose of the project and how to refer to the a service.

Communication with patients was more ad hoc; Liverpool and the North East and Cumbria Learning Disability Network were the only projects who reported systematically involving patients and the public in the planning stages of their project.

Formal evaluation of patient satisfaction was limited; for UCLH a survey was conducted by a London Cancer Intern and at Croydon Health Services NHS Trust by the Project Manager. All projects sought informal feedback from service users and anecdotal evidence of patient satisfaction was reported.

Airedale, Wharfedale and Craven CCG and Airedale NHS Foundation Trust attempted to get formal referrer (GP) feedback via a Survey Monkey questionnaire but the response rate was poor. Other projects sought to get informal feedback via the steering group (Croydon Health Services NHS Trust, and Liverpool).
The majority of projects sought referrer feedback at educational events/meetings. These included the North East and Cumbria Learning Disability Network, UCLH, Blackburn with Darwen and East Lancashire CCGs, Wrightington, Wigan and Leigh NHS Trust and Chesterfield Royal Hospital NHS Foundation Trust.

### 3.2.2.5 Engagement across all levels and organisational boundaries (Me)

Identifying and engaging with the right people from within their own and partner organisations was a key component of all successful projects. The scope of engagement varied between projects, some projects involved relatively few people from a small number of organisations. For Airedale, Wharfedale and Craven CCG and Airedale NHS Foundation Trust, their project only involved those two organisations. Clinical and managerial leads from both organisations already had professional relationships with each other and no new structures apart from a project steering group needed to be developed. Liverpool and the North East and Cumbria Learning Disability Network had large scale projects which crossed a number of organisational boundaries and involving a range of statutory and voluntary sector organisations. As a result they spent a significant amount of time mapping stakeholders and identifying their scope of influence, then building up relationships and structures and processes to work within prior to project implementation. In the remaining projects, the set-up work involved cultivating existing relationships in conjunction with developing some new ones, but in all cases the organisations involved where statutory health care providers.

### 3.2.3 Outcomes

We asked the key individuals in each case study to identify their intended outcomes prior to the start of their project. Some outcomes emerged that were common to all projects.
3.2.3.1 Successful implementation of project (O1)

Eight out of nine of the sites successfully implemented their projects. Some projects: Airedale, Wharfedale and Craven CCG and Airedale NHS Foundation Trust, Liverpool, Chesterfield Royal Hospital NHS Foundation Trust, UCLH and Wrightington, Wigan and Leigh NHS Trust were all aiming to normalise their projects. Normalisation is achieved when a process has been successfully implemented to the point where it has become custom and practice. At the time of the interviews being concluded these sites were at different stages of the normalisation process.

3.2.3.2 Faster route to diagnosis (O2)

Airedale, Wharfedale and Craven CCG and Airedale NHS Foundation Trust perceive that their Vague Symptoms project prevents patients being subjected to unnecessary or inappropriate radiological investigations and as a result has the potential to provide a faster route to diagnosis. At UCLH there is a perception that previously the patients accessing the vague symptoms pathway were being sent for wrong diagnostic tests initially, leading to delays in diagnosis or they were managed in primary care for an unnecessary amount of time. Feedback from GPs to the project lead indicates that they feel this is a faster route to diagnosis for cancer and non-cancer patients. A similar view was also provided by Chesterfield Royal Hospital NHS Foundation Trust. Anecdotal evidence from the Liverpool interviews suggests that cancer is being detected at an earlier stage. Preliminary analysis of data from this site supports this. Informants from Croydon Health Services NHS Trust reported that those patients who would previously have been placed on a non-urgent pathway were being seen more quickly. However due to increasing pressures on endoscopy services it is unclear as to whether this improvement can be sustained. For Wrightington, Wigan and Leigh NHS Trust, informants reported that for the straight to test patients the diagnosis is made more quickly, this is particularly noticeable in those with non-cancer diagnosis who are discharged on the day.
In all cases other than Liverpool, we can only report the subjective experience of some of those involved. However, the parallel quantitative evaluation being undertaken will provide objective evidence of the impact of these initiatives.

3.2.3.3 Improved patient experience (O3)

At the beginning of the evaluation all projects stated that they wanted to improve patient experience, however only two projects had formally evaluated patient experience at the end of the evaluation time frame; UCLH undertook a telephone survey of patients’ experience of the pathway, while in Croydon Health Services NHS Trust the project manager surveyed patients using a questionnaire whilst in the endoscopy department. Liverpool had patient surveys planned for the future and the majority of other projects felt this was something that should be considered for the future. Airedale, Wharfedale and Craven CCG and Airedale NHS Foundation Trust and Blackburn with Darwen and East Lancashire CCGs had projects that did not directly involve patients and whilst they aspired to improving the patient experience they did not have a way of measuring changes. All of the successful projects provided anecdotal evidence that patients valued the project and/or that referrers thought the project offered an improved patient experience.

3.2.3.4 Sharing good practice (O4)

All projects, including Queens Hospital, Romford, which was unsuccessful in implementing a pathway for vague abdominal symptoms, shared learning via their respective cluster group meetings. In addition, some projects such as Chesterfield Royal Hospital NHS Foundation Trust shared their experiences locally within local network meetings. Other projects including Wrightington, Wigan and Leigh NHS Trust, UCLH and Liverpool have shared their learning and experiences via posters and presentations at national conferences.

3.2.3.5 Sustainability (O5)

Not all projects set out to provide a service that would continue for the longer term. For example Blackburn with Darwen and East Lancashire CCGs aimed to reduce
barriers to cancer screening and ensure patients with learning disabilities were not inadvertently or erroneously excluded from cancer screening programmes. Activities relating to these aims occurred throughout one financial year and though there is an aspiration to repeat the activities at some point in the future, they were not intended to become an annual event.

At the time of the final interviews a number of the activities which were part of the North East and Cumbria Learning Disability Network project were work in progress. The intention was that these activities ultimately would be sustained and the network was in the processes of working with partner organisations to work towards putting plans in place to ensure long term sustainability.

Liverpool had developed a business case for support for ongoing funding which would enable their project to be extended to encompass other neighbourhoods. UCLH, Airedale, Wharfedale and Craven CCG and Airedale NHS Foundation Trust, Croydon Health Services NHS Trust, Chesterfield Royal Hospital NHS Foundation Trust and Wrightington, Wigan and Leigh NHS Trust had all secured ongoing funding and were continuing with the service as developed during the ACE project period.

4.0 Discussion

4.1 Organisational culture

Organisational culture is a system of shared assumptions, values, and beliefs, which governs how people behave in organisations. These shared values have a strong influence on the people in the organisation and dictate how they act and perform their jobs. The Kings Fund (2016) suggests that the following characteristics are fundamental to a healthy culture:

- Inspiring vision and values – leaders should communicate an inspiring, forward looking and ambitious vision.
• Goals and performance – goals should be set at every level from the board to frontline staff.

• Support and compassion – there are clear links between staff experience and patient outcomes. Staff views of their leaders are strongly linked to patients’ perceptions of the quality of care.

• Learning and innovation – sustaining cultures of high-quality care involves all staff focusing on continual learning and improvement.

• Effective team working - Effective team and inter-teamwork (both within and across organisational boundaries) is essential if NHS organisations are to meet the challenges ahead.

• Collective leadership – collective leadership means everyone taking responsibility for success of the organisation as a whole and not just for their own jobs.

All of the successful projects described elements of the healthy culture described above, though they varied in the extent to which these characteristics were evident. The most common characteristics described in the interviews were leaders communicating an ambitious vision, effective team working and continual learning and improvement. For some projects collective leadership was also a feature. None of the projects apart from Liverpool described goals being set from board level for frontline staff. Whilst no project specifically discussed support and compassion, interviewees from all successful projects talked positively about their leaders and the perceived effect the project had on the quality of care provided.

4.2 Commitment to quality improvement

The Kings Fund (2016) describes quality improvement as designing and redesigning work processes and systems to deliver health care with better outcomes and lower cost. It asserts that improvements in the quality of care do not happen by chance; they come from intentional actions by staff who have the skills to enable change. All of the successful projects had one or more individuals who had such skills and through motivation and commitment were able to drive and support change. Some
project teams were more familiar with improvement methodologies than others and this was often reflected in their level of success and their potential for sustainability. Kaplan et al (2010) identified a set of factors that are associated with success in quality improvement initiatives, shown in the table below:

<table>
<thead>
<tr>
<th><strong>Kaplan et al (2010)</strong></th>
<th><strong>ACE qualitative evaluation</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Leadership from senior management</td>
<td>This was a key facilitator for projects and lack of it was a barrier, particularly when high level or organisational issues, such as IT system incompatibility, arose.</td>
</tr>
<tr>
<td>Supportive organisational culture</td>
<td>A culture that is open to change and whose values are in line with those of the proposed initiative is much more likely to be facilitative than one where the organisation struggles with change or where the values are not aligned. See section 4.1 for more detail relating to organisational culture.</td>
</tr>
<tr>
<td>Data infrastructure and information systems</td>
<td>Important factors in quality improvement. Where information systems are aligned across organisational boundaries, e.g. Airedale, Wharfedale and Craven CCG and Airedale NHS Foundation Trust, it is much easier to exchange information. Systems which differ between partner organisations e.g. Croydon Health Services NHS Trust and Liverpool have the potential to become real barriers to progress. Both of these organisations spent an inordinate amount of time trying to address data infrastructure problems and ironing out data sharing agreements with partner organisations.</td>
</tr>
<tr>
<td>Previous involvement in quality improvement</td>
<td>All organisations reported previous quality improvement work and existing relationships with some if not all of their partners involved in the ACE project. Those developing additional new partnerships reported this as a facilitator as it generated enthusiasm for the projects.</td>
</tr>
<tr>
<td>Physician involvement</td>
<td>Clinical leadership was identified as an important facilitator in all projects, without consistent clinical leadership, projects failed to develop.</td>
</tr>
<tr>
<td>Micro-system motivation to change</td>
<td>In all successful projects interviewees described a professional gain as a result of implementing change. In</td>
</tr>
</tbody>
</table>
the unsuccessful project some interviewees were not motivated to change due to lack of job/role security or other work pressures taking priority. The successful projects also reported sharing a common belief in the value of the ACE programme.

<table>
<thead>
<tr>
<th>Resources</th>
<th>Funding from the ACE programme for additional resources in the form of project managers or data analysts was as a facilitator for those projects that received it. Please see section 3.2.23 for further detail on resource.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Team leadership</td>
<td>All successful projects identified champions at team level. In relation to the unsuccessful project, their champions became involved at a later date when the implementation challenges were too entrenched. See section 4.4 for more detail on leadership</td>
</tr>
</tbody>
</table>

4.3 Project Management

Project Management was identified as an important mechanism in all cases, however only one project (Liverpool) was able to describe in detail the method of project management they were going to use. Although all of the projects were part of NHS organisations, none referred to using the NHS change model which may have provided some structure to the projects. A systematic approach to project management is clearly important, and although formal models were not evidenced during the interviews those projects with a systematic approach were more effective than those with a more *ad hoc* approach. Time spent thinking about what the projects wanted to achieve and how they were going to achieve it varied significantly between projects, as did the amount of documentary evidence to support that thinking.

Some projects were better at anticipating challenges and dealing with problems than others, those who anticipated problems had already developed a range of plans for dealing with them, whilst those projects who were less good at anticipating problems often had a more reactive approach. In some instances, problems had to go back to the steering groups for discussion and resolution. When this happened
this it sometimes led to delays. This suggests that it would be useful for projects to consider in advance how they will reflect on progress and react to challenges.

All of the projects considered capability and capacity to some extent, they all thought about the clinical skills required to deliver the project and to some extent the need for project management skills, whether they existed within the team or whether additional expertise was needed. Other skills, such as in-depth knowledge of improvement methodologies or change management theory, were considered much less frequently, although nearly all interviewees reported previous experience of improvement work.

4.4 Leadership

The NHS Institute for Innovation and Improvement (2011) has highlighted the distinction between management (getting the job done), and leadership (the art of motivating people toward a common goal). They also cite evidence from studies which indicate correlations between high quality management and leadership and a range of outcomes, including higher quality patient care and improved productivity.

Transformational leadership was the most prevalent style of leadership described by the interviewees. Transformational leadership works well when trying to implement complex change as it is more appropriate in fast changing situations, where people have high levels of skill and where the leader can afford to get involved in the detail. As well as creating a vision, transformational leaders create opportunities for people to show flair and to take responsibility for new ideas; this style of leadership also empowers people to deal with challenges in a proactive and timely manner which has been a key factor identifiable in the successful projects. This style of leadership works well when implementing complex interventions such as the ACE projects because it is not reliant on one individual and it allows individuals to work to their strengths whilst developing new skills. Transformational leaders are often very extravert, charismatic and strategic, and in addition to being passionate about quality improvement these traits where identified in their leaders were identified by interviewees from a number of the successful projects.
Transactional leadership theory is based on exchanges between the leader and the follower. It assumes that the working relationship is one where the leader issues the work and praises or criticises accordingly. The follower has little responsibility, other than doing as they are required, correctly. All works well if both leader and follower carry out their part in the exchanges as expected. This style of leadership, which is not suited to complex situations or those where the followers are highly skilled and/or used to working autonomously, was observed in the one project which was unsuccessful.

4.5 Sustainability

Of the projects demonstrating elements of successful implementation, the North East and Cumbria Learning Disability Network and Blackburn with Darwen and East Lancashire CCGs never intended their projects to be continued long-term. Chesterfield Royal Hospital NHS Trust has been running their service for a significant amount of time and as a result it was already established (although interviewees did describe ongoing operational issues relating to Specialist Nurse cover) when it became involved with the ACE programme, it was therefore inappropriate to apply normalisation process theory to that project. Our analysis shows that Airedale, Wharfedale and Craven CCG and Airedale NHS Foundation Trust have implemented or normalised their project to a degree where it well accepted by those using the service (GPs) and those providing the services from within secondary care. Funding has been secured to support ongoing provision of the service and there is sufficient evidence to suggest that this service should be sustainable. Indeed, this service was expected to influence the design of their ACE wave 2 project.

UCLH, Wrightington, Wigan and Leigh NHS Trust, Croydon Health services NHS Trust and Liverpool were all at different stages of the normalisation process. UCLH were experiencing some staff changes at the time of the final interviews and the new CNS and MDC pathway co-ordinator needed to become established in their roles before complete normalisation and sustainability can be assured. Wrightington, Wigan and Leigh NHS Trust needed to ensure a sustainable way of ensuring endoscopy slots lost
as a result of clinicians annual leave are routinely backfilled. Croydon Health Services NHS Trust also had an issue with endoscopy capacity, as demand was exceeding available capacity. A business case had been developed to provide more capacity, something that would be necessary to ensure long term sustainability of the project. Other elements of the pathway appear to have been normalised. Liverpool’s is a longer term project, however many elements of the pathway have been normalised. The threat to sustainability in the longer term may be radiology reporting capacity.

Many of the steering groups were considering disbanding or changing their focus to encompass other things by the final set of interviews, there is a risk that without that degree of oversight and scrutiny some practices may not be sustained, (Greenhalgh et al, 2012)

5.0 Conclusion

Eight out of nine sites successfully managed to implement their projects, a gratifyingly high level of success for this type of complex project implementation. It may be explained by the fact that ACE asked for interested parties to apply to the programme, so the sites that submitted expressions of interest were already motivated to implement their projects. They had all already identified the issue they proposed to address as one of local and in some instances national importance and all of them, with the exception of UCLH and Queens Hospital, Romford, had started working on a solution to their particular issue. Indeed, many would have implemented their project regardless of ACE because they had individuals who wanted to change existing systems and processes and who were passionate and committed to quality improvement.

The involvement of ACE may have contributed to the successful implementation in a number of ways. Firstly, all projects except Chesterfield Royal Hospital NHS Foundation Trust received some funding from the ACE programme; many projects used this to fund Project Managers or data analyst support, though some used it to fund activity. Secondly, some projects found it useful to gain board level support by
describing the interest in and scrutiny of the ACE programme from a national cancer and policy making perspective. Thirdly, the support and sharing that occurred within the cluster groups was seen as invaluable by some of the projects.

There have been a number of challenges to implementing the ACE projects and to ensuring their longer term sustainability:

5.1 Engaging clinicians and developing clinicians as leaders

Clinical engagement was key to successfully implementing projects. Where clinical leaders are proactive and identified with stakeholders, interviewees report better engagement. However leaders do not always have change management skills or knowledge of quality improvement methodologies and there is value in developing that capacity at a local level. There is also some merit in projects considering the type of leadership required to ensure that stakeholders maintain their enthusiasm and engagement.

5.2 Change takes time

There is an acknowledgement that change takes time, and that there needs to be a significant amount of repetition and sustained support to achieve change. There is value in learning from others who have previously tried to implement something similar as understanding what worked for whom and in what circumstances can cut down on unnecessary wasted time.

5.3 Skills

The skills required to deliver these projects are multiple and sometimes diverse. All projects required individuals to have leadership and management skills to ensure their project was successfully implemented, they also needed clinicians with the technical skills to deliver the chosen intervention, but the most successful projects also needed additional skills such as being able to understand and use quality improvement methodologies and influencing skills. The need for influencing skills was particularly relevant in the implementation of large scale projects such as the Liverpool and North East and Cumbria Learning Disability Network projects which
resulted in the need to develop partnerships with new organisations as well as organisations where partnerships previously existed. These organisations have different cultures and targets and project leads have needed to develop different skills in order to be able to understand and influence them. Knowledge of improvement methodologies would be beneficial for all project leaders/managers.

5.4 Short-termism

Financial pressures, fixed term funding and fixed term contracts encourage short-term thinking and key stakeholders may be reluctant to ‘buy in’ to an initiative if they lack assurances that funding will be continued in the long term. The short term nature of the ACE projects meant that had minimal data relating to their initiative or had not completed their planned internal evaluation as the project neared its end date. The large amount of organisational change which occurred at Queens Hospital, Romford during the evaluation period were a significant distraction for some parts of the Trust’s organisation, to the detriment of the ACE project.

5.5 Recommendations:

Any sites wishing to implement complex service improvement of the type promoted by the ACE programme should consider:

- Ensuring in advance that there is buy in from all the partner organisations and the key individuals who will deliver the service
- Testing receptiveness to change among users, providers and patients.
- Investing time to secure commitment to developing and implementing the service
- Investing time to develop the strategy to achieve the service improvement
- Ensuring that the additional resources needed to deliver the new service are identified and secured.
- Investing time in developing and maintaining relationships between and within participating organisations
• Investing time to reflect on progress and build in the ability to react to challenges as they emerge
• Investing time and resources to develop the necessary technical, organisational and leadership skills.
6.0 References


Greenhalgh T, Macfarlane F, Barton-Sweeny C, Woodard F. “If We Build It, Will It Stay?” A Case Study of the Sustainability of Whole-System Change in London. The Millbank Quarterly 2012; 9 (3): 516-547


May C. A rational model for assessing and evaluating complex interventions in health care. BMC Health Serv Res. 2006;6:11.


## Appendix A Glossary

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>2WW</td>
<td>2 Week Wait</td>
</tr>
<tr>
<td>ACE</td>
<td>Acceleration, Coordination and Evaluation</td>
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<tr>
<td>CCG</td>
<td>Clinical Commissioning Group</td>
</tr>
<tr>
<td>CHS</td>
<td>Croydon Health Service NHS Trust</td>
</tr>
<tr>
<td>CMO</td>
<td>Context Mechanism Outcome</td>
</tr>
<tr>
<td>CNS</td>
<td>Clinical Nurse Specialist</td>
</tr>
<tr>
<td>COPD</td>
<td>Chronic Obstructive Pulmonary Disease</td>
</tr>
<tr>
<td>CQIN</td>
<td>Commissioning for Quality and Innovation</td>
</tr>
<tr>
<td>CRESS</td>
<td>Croydon Referral Support Service</td>
</tr>
<tr>
<td>CRUK</td>
<td>Cancer Research UK</td>
</tr>
<tr>
<td>CSU</td>
<td>Commissioning support unit</td>
</tr>
<tr>
<td>CT</td>
<td>Computerised Tomography</td>
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<tr>
<td>CUP</td>
<td>Cancer of Unknown Primary</td>
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<tr>
<td>DABO</td>
<td>Direct Access Bowel Oscopy</td>
</tr>
<tr>
<td>DNA</td>
<td>Did not attend</td>
</tr>
<tr>
<td>GI</td>
<td>Gastrointestinal</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>LD</td>
<td>Learning Disabilities</td>
</tr>
<tr>
<td>LD DES</td>
<td>Learning Disabilities Directly Enhanced Service</td>
</tr>
<tr>
<td>LIS</td>
<td>Local Improvement Scheme</td>
</tr>
<tr>
<td>MDC</td>
<td>Multidisciplinary diagnostic clinic</td>
</tr>
<tr>
<td>MUO</td>
<td>Malignancy of Unknown Origin</td>
</tr>
<tr>
<td>NICE</td>
<td>The National Institute for Health and Care Excellence</td>
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<tr>
<td>NPT</td>
<td>Normalisation Process Theory</td>
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<tr>
<td>PAS</td>
<td>Patient Administration System</td>
</tr>
<tr>
<td>PID</td>
<td>Project Initiation Document</td>
</tr>
<tr>
<td>PM</td>
<td>Project manager</td>
</tr>
<tr>
<td>PRU</td>
<td>Policy Research Unit for Cancer Awareness, Screening and Early Diagnosis</td>
</tr>
<tr>
<td>Acronym</td>
<td>Description</td>
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<tr>
<td>---------</td>
<td>-------------</td>
</tr>
<tr>
<td>QUIPP</td>
<td>Quality, Innovation, Productivity and Prevention</td>
</tr>
<tr>
<td>RAIDR</td>
<td>Reporting Analysis and Intelligence, Delivering Results</td>
</tr>
<tr>
<td>SOP</td>
<td>Standard Operating Procedure</td>
</tr>
<tr>
<td>STT</td>
<td>Straight to test</td>
</tr>
<tr>
<td>UCLH</td>
<td>University College London Hospitals</td>
</tr>
</tbody>
</table>
Appendix B Colorectal Cluster Case Studies

B.1 Croydon Health Services NHS Trust and Croydon CCG direct access service for colorectal symptoms

In this case study we describe the processes involved in implementation of a direct access service for patients in Croydon with high risk colorectal symptoms, as part of the ACE programme. The project is ongoing and this qualitative evaluation covers the period to June 2016.

B.1.1 Introduction and Background

Croydon Health Services NHS Trust serves the London borough of Croydon. The borough has a population of over 360,000 people in an area covering 87 square kilometers and their healthcare needs are met by 58 GP practices and Croydon University Hospital, a district general hospital which has a range of outpatient and inpatient services. The hospital has 670 hospital beds, 589 of which are for acute admissions.

Croydon is the largest and one of the most diverse London boroughs. There are significant health inequalities in Croydon; in its more prosperous areas, older people enjoy twice as many disability-free years than in the poorer areas.

Croydon Health Services NHS Trust has had a history of reviewing and redesigning pathways, particularly those related to cancer. It has been delivering a ‘straight to test’ service for 2 week wait (2WW) referrals since January 2003, with their experience being reported in the Annals of the Royal College of Surgeons of England (Beggs et al, 2011).

The evolution of the ‘straight to test’ service was as follows:

- ‘Straight to colonoscopy’ (no triage) for 2WW referrals from 2003
- Nurse-led ‘Straight to flexible sigmoidoscopy’ service for patients aged >50 with rectal bleeding from 2011
- ‘Straight to test’ with triage for 2WW referrals from 2011
- GP led (triage by GPs) service’ straight to flexible sigmoidoscopy or colonoscopy’ established in 2015.

Croydon Health Services NHS Trust, NHS Croydon Clinical Commissioning Group and the London Cancer Alliance had worked closely to develop a Direct Access Bowel Oscopy (DABO) Service, which coincided with the ACE programme’s call for expressions of interest.

For the ACE programme these partners set out to develop a one stop, direct access service for patients with rectal bleeding. It was intended that the service would provide an improved patient experience by reassuring those patients with benign disease and offering management where possible at the time of endoscopy, for example, banding haemorrhoids, thus reducing the need for further follow up. The
‘straight to test’ service required the GP to assess the patient against specific criteria, explain the procedure, consent the patient and prescribe the bowel prep.

There was a general view that the DABO Service would have gone ahead irrespective of the ACE programme, though the pace of implementation might have been different. There was also a perception that being labelled an ACE project brought with it some kudos and acted as a driver when trying to engage people. The new ‘straight to test’ pathway is linked to Best Practice Commissioning for early diagnosis of colorectal cancer, as recommended by the Transforming Cancer Services for London programme and further endorsed in the Five year Commissioning Strategy for London (2014, NHS England).

**B.1.1.1 Aims and Objectives**

To establish a “one stop, direct access service” for the diagnosis of rectal bleeding and other high risk symptoms to promote the early detection of bowel cancer.

The aim of implementing their service was to have a patient pathway which focused on early diagnosis and which provided improved patient experience. It was also hoped to improve integration between primary and secondary care in relation to patients with colorectal symptoms.

**B.1.1.2 ACE model**

A Primary Care Rectal Bleeding Pathway was agreed between Croydon Health Services NHS Trust and NHS Croydon Clinical Commissioning Group that aimed to direct patients to the most appropriate diagnostic test, dependent on them meeting the agreed referral criteria.

A new pathway with associated referral criteria and referral forms was developed where patients were referred directly from primary care to endoscopy; this involved patients being assessed against the following criteria:

- Urgent referral (seen within six weeks) for rectal bleeding alone (without change in bowel habit without anal symptoms) of any duration in patients aged over 40 years
- Rectal bleeding alone (without change in bowel habit, without anal symptoms) aged under 40 years, and unimproved after following the primary care hemorrhoid pathway
- Other rectal bleeding that does not meet 2WW or urgent six week criteria, or hemorrhoid or anal fissure pathway criteria

Exclusions to this pathway were based upon clinical judgement and included poor mobility/performance status and abnormal clotting indices.

The GP then sends the referral to a local referral management service who was responsible for checking that the form has been completed accurately. Where information is missing the GP was contacted and requested to supply the missing information. Once the information was complete the referral was sent to a
dedicated nhs.net email address which was checked twice per day. The patients were then telephoned and offered an available slot to attend the DABO clinic. On arrival at clinic a brief check was conducted prior to the procedure. Patients had the procedure; where appropriate they were given advice, reassured it was not cancer and discharged. Those requiring simple interventions had them done within the appointment and discharged. Those with more complex problems e.g. those with suspected cancer were upgraded to the cancer pathway. Patients with significant non-cancer diagnoses were referred on to the appropriate specialty. Results were sent to the GP for management. All GPs were be advised of the referral outcome and given management advice as appropriate.

With the exception of removing the age threshold for investigation, the new pathway was consistent with NICE guidelines.

The pathway was heavily reliant on Croydon Clinical Commissioning Group’s ownership as the GPs were required to play a key role at the start of the pathway. The GP was required to assess the patient’s symptoms, performance status and fitness for the 'straight to test' procedure and then refer to the appropriate test. The onus was on the referring GP to perform the relevant blood tests and to advise the patients about the procedure as well as prescribing the appropriate bowel prep.

It was felt that this project was appropriate for the ACE programme because of its potential to reduce waiting times and the potential to test direct access diagnostic services for people with rectal bleeding regardless of potential cause, it was also hoped to be the prototype for a wider roll out of direct access services across the London Cancer Alliance constituent organisations and beyond.

**B.1.1.3 Project Scope**

A project manager was appointed for one year from April 2015 to support implementation and evaluation.

**B.1.1.4 Implementation**

At the planning stage of this project it was identified in order to ensure a robust process of implementation the need for a project manager. An experienced Project Manager with substantial NHS experience was appointed on a part-time, one year fixed term basis using ACE funding. The project manager was a dedicated role solely focused on getting the project up and running, addressing problems and ensuring embedding and sustainability of the project. In addition a steering group including key stakeholders from secondary care, primary care and the CCG was established to ensure a range of governance issues were addressed, these included:

- Outcomes & Evaluation
- Information Management and Technical (IT)
- Information Governance (IG)
- Finance, Contracts & Procurement
- Engagement & Communications
• Service Delivery (including clinical pathways)

The Steering Group was also responsible for the management and monitoring of the project, it was intended to control the realisation of the project at the strategic level and verify the project’s coherence with established aims.

The service commenced at the end of June 2015.

Mid-way through the project a Data Analyst was also appointed to support data collection and analysis and service evaluation.

B.1.2 Methodology

The qualitative evaluation of the ACE programme draws on the principles of realist evaluation (Pawson and Tilley, 1997) to develop a contextualised account of the way in which change emerges. See section 2.1 for details of realist methodology. For the purposes of this case study, a total of 22 1:1 interviews with key informants were carried out.

Analysis of the interviews resulted in the development of a Context, Mechanisms and Outcomes (CMO) model (figure 2)

The CMO model considers the contexts, mechanisms and outcomes that were apparent in the implementation of the initiative. Each of the key mechanisms is considered in turn within the case study.

Normalisation Process Theory (NPT) provides the theoretical basis for understanding how the initiative is understood, implemented and embedded into normal practice. NPT considers four areas; coherence, cognitive participation, collective action, and reflexive monitoring. See section 2.2 for details. Each of these areas are considered in turn in table 4.
Figure 2 CMO model for Croydon Health Service NHS trust and Croydon CCG Direct Access Service for colorectal symptoms

N.B. We do not specifically discuss the second cluster M1-M5 because they are components of the mechanisms discussed Ma-Mh

B.1.3 Contexts, Mechanisms and Outcomes (CMO)

B.1.3.1 Service/pathway design (Ma)

Context and Mechanisms

A new pathway the detail of which has been described in section A.1.1.2 was developed and implemented.

When the project commenced there were a number of management pathways in existence relating to colorectal symptoms, making it confusing for GPs who wanted to refer. There had also been a published account of colorectal pathway development to inform the evidence base.

On interviewing representatives from the CCG it became evident that they thought the pathway being proposed had been implemented some time previously and that it was a fully commissioned service. As a result significant frustration relating to the delay in implementation of a fully operational pathway was evident during the first set of interviews.
Characteristics of mechanisms and outcomes

The development of the direct access service involved a number of stages including; developing a Project Initiation Document (PID); engaging with stakeholders; establishing a steering group, identifying monitoring metrics and the provision of day to day leadership and support, all of which were facilitated by the project manager.

A new pathway with associated referral criteria and referral forms was developed where patients were referred directly from primary care to endoscopy. The pathway is described in B1.1.2.

The process of implementing the new pathway was iterative, with increasing levels of compliance. Initially large numbers of referrals were rejected due to being incomplete. This improved significantly over time as the Project Manager and Data Manager provided feedback to referrers each time a referral was incomplete:

“The GPs now have the knowledge of how to really fill in the GP referrals, the referrals have increased and the returned forms decreased, in December we were having 20-25 referrals (forms) which were rejected (due to insufficient information), January we had 24, February we had five, and now it’s the 16th (March) today and I’ve only had one where we have needed more information”

Administrator

Patients were asked to complete a satisfaction survey after their procedure had been completed:

“Patient satisfaction was 100% in January . . . . . . . most of the patients are really, really satisfied with the service that they’re getting from the endoscopy unit. Most of them would like to come back and they like the staff as well”

Data Analyst

Interviewees believed that introducing the ‘straight to test’ pathway had reduced the time from date of referral to first investigation for non-2WW referrals.

Interpretation

The implementation of this pathway has been gradual. When the first set of interviews was conducted, buy-in from the GPs was patchy, as was compliance in terms of completing referral forms in the correct manner. By the final set of interviews, which were conducted approximately eight months later, the different professional groups involved in the delivery of the pathway largely understood what was involved to deliver the pathway. It is notable that both the Endoscopy Manager and one of the Clinical Commissioning Group Managers were surprised at the initial spare capacity whilst the pathway was being introduced. Had this been considered prior to implementation, it may have been possible to use the vacant slots differently or divert staff to other activities on a short term basis.

Some of the colorectal pathways have been streamlined as a consequence of this work; however multiple colorectal pathways still exist in Croydon.

Using Normalisation Process theory to interpret our interview findings, we observed that cognitive participation was enhanced as staff could see both immediate and longer-term benefits to patients and practice. High levels of cognitive participation
then helped to engage staff in collective action, although minimizing the amount of work required is also vital. The Project Manager was particularly instrumental in trying to minimize the disruption to pre-existing practices and workflows.

Reflexive monitoring was enabled through the establishment of a steering group and provision of regular feedback relating to updating on systems and process development and activity.

The pathway has been adopted. Reflexive monitoring has resulted in changes to the SOP and more recently has led to closer scrutiny of data in relation to other related pathways. The focus of the steering group also widened to encompass upper GI referrals and was supported by a new set of terms of reference to help it address a wider, though related agenda.

**B.1.3.2 Evaluation of capacity (Mb)**

**Context and Mechanisms**

Prior to implementation of the ACE project, Croydon had multiple lower GI referral pathways. Endoscopy slots were often wasted due to patients being booked in for the wrong examination and as a result having to be sent home and so endoscopy capacity was an important context. There was recognition that this needed addressing and pathways needed reviewing:

“It’s disappointing that you can book patients in and now that there’s a likelihood that some of those will be referred inappropriately, which means that they won’t have the procedure on the day, it’s wasted theatre capacity, it’s also not brilliant from a patient perspective”

Endoscopy Manager

At the start of the project, the endoscopy manager was approached to help identify a vacant list at the time of an existing outpatient clinic which could be utilized for the new pathway.

**Characteristics of mechanisms and outcomes**

There was no free list available at the time required:

“I had no available theatre slot on a Tuesday afternoon. So the barrier was (a) trying to negotiate around is there any movability around moving the day that the colorectal team could do, that couldn’t be done. So then it was around looking to see what I could try to move to another day, luckily I’ve got good relationships with my operational manager, colleague in respiratory medicine, it ended up where we had some conversations with her and the consultants in respiratory medicine, and they agreed to move their Tuesday afternoon session to a Wednesday afternoon instead.”

Endoscopy Manager

When the service initially started it wasn’t being well utilized:

“We found that lists were going unfilled in the beginning, as an operational manager in endoscopy, and with the pressures around two week waits and theatre capacity
and finding operators, it was very frustrating on my behalf that after doing so much negotiation with other services the lists were going unfilled and we were unable to utilize staff’

Endoscopy Manager

However, as the pathway became more embedded and by the second set of interviews there was no evidence of un-utilized capacity:

“The service is up and running and appears to be working well”

Service Manager

“Everything is working well, with capacity being utilized, endoscopy is working well”

Project Manager

When the final set of interviews were conducted there was evidence to suggest that endoscopy capacity had become a real pressure:

“Everything is working except capacity”

Administrator

“Capacity is insufficient to meet demand, in that sense we have become a victim of our own successes”

Project Manager

In response to challenges related to meeting endoscopy demand for this service as well as others, a range of solutions had been implemented or were being considered:

“I think we’ve got a better understanding of capacity. The Trust has now put £197,000 towards new scopes and to look into – they’ve got four theatres at the moment - to redo a fifth one to try and work through the capacity issues, We’re doing Saturday morning, but now we are pushing into doing seven days a week and maybe some evenings as well, this is also linked to the implementation of the new cancer guidelines”

Commissioning Manager

There was some confusion between stakeholders in relation to outpatient activity. There was a general acceptance that the data currently available was inaccurate and of poor quality. During the initial interviews it was evident that a desired outcome for Croydon Clinical Commissioning Group was the reduction of outpatient appointments resulting from the implementation of the ‘straight to test’ pathway, potentially reducing costs. However, from a Croydon Health Services NHS Trust perspective the desired outcome focused on an improved patient experience via the reduction of unnecessary outpatients’ appointments i.e. the majority of patients would be seen once in the one stop clinic thus reducing multiple visits for patients with straightforward, benign disease. In addition to this aspiration the secondary care lead clinician always anticipated an increase in the numbers of outpatient referrals due to the reduction in the referral threshold:

“Now what we are telling the GPs now is that, hang on, as soon as you see a patient aged 40 and above with rectal bleeding, please don’t faff about. Do not give them medicines . . . . just send them across for diagnostics. So these groups of patients did not used to come and see us before and that’s what the CCG does not understand,
there is a group of patients that normally used to come to clinic, which obviously as a result will be encompassed by this criteria and then they will come for flexible sigmoidoscopy, but equally so, there are a new group of patients that this pathway caters for and asks the GP to send them across immediately without delay so a measure of success of this pathway is not about a reduction in outpatients attendances. That may well be the case in two or three years later, but certainly it’s not like for like”

Clinical Lead

In order to address the concerns about there being no reduction in outpatient referrals alongside the increase in direct access endoscopy, the commissioners stated that referrals to outpatients were to be stopped:

“For the direct access one stop shop, that pathway was running as well as the old outpatient pathway, so both pathways were running together . . . . . . . . . so now we’ve had to draw a line and from the 1st April we’ve said the old pathway has to stop running and a new pathway is obviously, the GPs have to manage the patients routinely for eight weeks in primary care and then go through the pathways that have been signed off”

Commissioning Manager

Another way of managing capacity, which was raised during the second and third interviews was the appointment of a triage nurse. A business case was developed and supported in principle by the Croydon Clinical Commissioning Group. Although this was discussed at length in the steering group and at business planning meetings, it has become evident that there were different perceptions of the role and function of that post:

“We’re looking to put triage nurses in for both upper and lower GI, so we get sort of a gatekeeper to send referrals back routinely for patients who haven’t followed the primary care pathway and to direct them to the correct tests”

Commissioning Manager

This function is not needed in a Direct Access pathway and when affirmation of this was sought from the lead clinician he responded:

“No, no, no, no, absolutely not . . . . . . . our pathway . . . . it’s about educating GPs and GPs referring directly to our service, full stop . . . . with no triage or anything. Ok it’s just a direct referral. The only triage was to triage the forms not the criteria”

Lead Clinician

Interpretation

Our analysis shows that there has been a mismatch of expectations as to the impact of increased demand on both endoscopy capacity and outpatient referrals. Although capacity has been a theme which has emerged in all sets of interviews there was no evidence that any capacity modelling was conducted prior to implementation of the pathway. Since implementation and adoption of the pathway there has been a growing realisation by all parties that demand far outweighs capacity. It is unclear as to what data the plan to increase capacity will be based on.
B.1.3.3 Introduction of new roles (Mc)

\section*{Context and Mechanisms}

A Project Manager was appointed as detailed in the implementation section of this case-study. Initially, in addition to the Project Manager, a member of bank staff was identified to book patients and support data collection, however it soon became evident that the person fulfilling the role was disengaged and struggling to implement new processes and procedures. As a result, relatively early on in the project, it became evident that that there were significant problems relating to booking patients, inputting and retrieval of data so a business case for a Data Manager was developed. This person was appointed mid-way through the project.

Continuity of support staff has also been an issue. Initially with the administrative and data management support to the project, although this was subsequently resolved. The support from the CCG has also lacked consistency; three different CCG Commissioning Managers with differing levels of expertise and input into the project were interviewed throughout the evaluation period (there had been two involved in the pathway development prior to that), all of who had a slightly different perspective on the issues and their role in relation to the project.

\section*{Characteristics of mechanisms and outcomes}

The Project Manager post was appointed to in April 2016 on a one year fixed term contract. The role involved:

"Implementing the Direct Access Proctology Clinic and it involves starting from the referral from the GPs to ensure that the correct referrals are coming in and making sure there is adequate resource in secondary care to be able to deal with those patients, and looking at how to manage the actual operational process of it”

\begin{flushright}
Project Manager
\end{flushright}

The Project Manager worked very closely with the CCG as well as colleagues in secondary care and was valued by key stakeholders:

"YYY (the Project Manager) has been a great success and a great help. She saved me battles with the Trust because she was having them on the projects behalf, if you like and coming and dealing with me . . . . . I honestly don’t know what is going to happen once YYY leaves”

\begin{flushright}
Lead Clinician
\end{flushright}

"The project manager has been taking forward the steering groups and things. . . . . It’s been good to have YYY (Project Manager) because she’s been that consistent approach. So that’s kind of what mainly I think we need, just to have a bit more joined up working between CHS [Croydon Health Services NHS Trust] and the CCG around how we are taking this forward, I think I can see from the reports that YYY has written, they’re doing a lot of stuff over at CHS end about what needs to happen”

\begin{flushright}
CCG Commissioning Manager
\end{flushright}

Many key stakeholders referred to how they had worked with the Project Manager in order to ensure successful implementation of this project, a number also
expressed concerns about the sustainability of the project once the Project Manager had left:

“*I’m not sure what is going to happen when she’s gone, she’s put systems and processes in place to ensure different individuals are responsible for elements of the work, but I’m not sure where the oversight is going to come from, probably via the steering group.*”

Cancer Manager

The Data Manager came in to post in September 2016 and her role was to:

“*Book the patients and manage the database and to analyse the data and everything*”

Data Manager

At the time that she came into post it was almost impossible for the project team to access any meaningful data using existing systems and processes; as a result she initially focused on some remedial work:

“*So XXX came into post in September and all she did was go back and access different systems just trying to get the data. So there has been a lot of work that went on*”

Project Manager

The role of the Data Manager changed towards the end of the project when the booking of patients was devolved to another administrative role within the colorectal service.

Initially the lead clinician was solely responsible for the Direct Access Service as he wanted to maintain initial control in order to address any initial problems and ensure quality assurance measures were robust:

“*I know Mr A (Lead Clinician) is attending the lists himself in this initial period whilst the service gets off the ground, just to make sure that any teething problems he’s aware of and he can work through before letting the registrars take over the list. So it’s been very good that we’ve had that, it’s been a consultant led clinic initially. And that’s also helped to provide some confidence and reassurance I think to the nursing staff and everybody in endoscopy around what the new list is, what the service is, the purpose of it.*”

Endoscopy Manager

“So there are all these sort of barriers that we have and I won’t say that it is as smooth as it is and that’s why I personally, before I roll it out across the hospital. I am personally involved in all the clinics at this moment in time, to iron out any issues and streamline the pathway “

Lead Clinician

As time progressed Specialist Registrars shadowed the Lead Clinician and gradually become involved with the pathway.

**Interpretation**

Although initially there was a view that this project would have happened even without ACE funding, due to lack of lead clinician capacity it is unlikely that the project would have come to fruition without the additional capacity created by the development of the Project Manager and Data Analyst roles.
Sustainability of the project remains a concern. The systems and processes exist to ensure the pathway can operate but the oversight of the pathway, data analysis and review has now been devolved to a range of individuals all of whom have a number of other responsibilities.

During the evaluation period the CCG appears to have undergone significant change, with 3 people occupying the post responsible for supporting this initiative. These changes in staff have resulted in some loss of organizational memory, some miscommunication and a need to repeatedly reiterate important decisions.

**B.1.3.4 Multi-level, cross-organisational engagement and commitment (Md)**

**Context and Mechanisms**

Whilst Croydon Health Services NHS Trust led the project, Croydon Clinical Commissioning Group involvement was also crucial as they were key to engaging with primary care to ensure the implementation of the pathway; they also had a subsequent monitoring role. The project was also identified as a Quality, Innovation, Productivity and Prevention (QIPP) project.

There was evidence of a lack of clarity in terms of a project start date despite regular communication between the project lead and CCG representative. The first CCG lead interviewed highlighted the perceived delay in implementation and the number of people previously involved from a CCG perspective:

“I wasn’t involved in the beginning . . . . it should have been launched 15 months ago . . . . So I’m third in line on this project . . . . . so the senior manager handed it over to me, as one of the managers of the team put it, with a bow round it, wrapped in gift paper. So this was a fantastic project all set up and ready to go, everything was, there’d been a few obstacles to overcome and so forth. But as we’ve moved forward we’ve discovered various issues with the project that we were not aware of.”

CCG Lead

The misunderstandings relating to the perceived start date of the pathway resulted in a degree of disharmony between the two organisations and a significant amount of frustration was evidenced throughout the interviews:

“So we launched the pathway last March. So some of it has been running but some of it’s still only just being implemented, which we found out when YYY (the project manager) went in, so we have commissioned a service and there’s a QIPP element to it, because it dramatically reduces first to follow ups, and that sort of thing, but it’s just not been implemented properly at the Trust, which is deeply disappointing.”

CCG Chair

“I think there have been some misunderstandings with the CCG in terms of where we are with implementation and that’s been frustrating to say the least.”

Clinical Lead
The Project Manager role was intended to provide continuity and capacity to address issues related to project implementation, she did this primarily through raising the profile of the pathway in a range of settings and liaising with key stake holders using a range of mechanisms including one to one meetings, developing a steering group and education sessions.

**Characteristics of mechanisms and outcomes**

**One to one meetings**

The Project Manager initially met regularly with the CCG to iron out some of the initial problems and ensure buy in from a CCG perspective:

“I haven’t had to work hard to engage the CCG . . . . . this project it’s really supported by the CCG and it’s a service that is commissioned by them with a carrot at the end of it which is the CQIN [Commissioning for Quality and Innovation] money. So there is a lot of impetus in getting this service up and running and embedded . . . . . the challenge was to iron out misconceptions and get everyone to appreciate the issues involved, but I just kept meeting with people and repeating the messages.”

Project Manager

Skilled communication was particularly important in getting everyone to understand the main issues in preventing full implementation of the pathway. The Project Manager was crucial to ensuring everyone was working together and in a cohesive manner to address the problems. Interestingly, she was perceived as being a credible and neutral figure by the CCG even though she was employed and managed by secondary care, this seems to have helped reduce some of the initial tensions evidenced between the CCG and secondary care in the initial set of interviews:

“So now YYY (Project Manager) is holding them (secondary care) to account and starting to do it properly”

CCG Chair

The Project Manager also regularly met with a range of staff affected by the implementation of the pathway, this ranged from regular formal meetings to informal, *ad hoc* conversations to address a wide range of issues, from agreeing administrative processes to identifying endoscopy capacity. These discussions resulted in formalizing systems and processes and the production of SOPs and protocols to support implementation of the pathway.

The one area where this approach did not appear to be effective was in terms of resolving the multitude of problems relating to information systems, at the time of the final interviews problems relating to inadequate information systems were still prevalent and as a result the issue had been escalated to board level for resolution.

**Steering group**

A steering group was established including key stakeholders soon after the Project Manager commenced her post:

“We have a steering group . . . . the CCG Chair chairs it jointly with our Clinical Lead . . . . I do the supporting alongside my CCG counterpart. We have invited the
commissioners, commissioning manager from the CCG . . . . when we have an issue with something like Finance or Public Health we invite them . . . . but general membership is around secondary care, and we’ve got management, risk, audit, clinical, nursing and cancer. So it’s a group that sat together and decided what its aims and purpose was . . . . but when we’ve got an issue we will invite people in and have a task and finish group”

Project Manager

The Lead Clinician was initially single handedly responsible for the implementation of this pathway.

**GP Practice visits**

A number of GP practice visits were undertaken by the Clinical Lead and the Project Manager, with the Clinical Lead talking to GPs and the Project Manager speaking to Practice Managers. These visits proved successful in getting practices to use the pathway and also to reduce errors when completing the referral forms.

The GP visits also helped the secondary care staff understand where there were issues from a primary care perspective:

“We’ve done Practice visits which evaluated very well and when there have been issues with individual practices usually around the referral forms or something I’ve offered to visit them and that seems to have been well received.”

Project Manager

“Visiting the practices obviously helped, if you like bringing GPs in direct contact with the people that are doing it (the endoscopy). And also visiting the GPs allowed me to look at their end of the pathway; in other words what they see when they refer these patients. And we’ve picked up a couple of issues, and in fact today I’m supposed to go, to have gone to the CCG to look at the software.”

Clinical Lead

**Liaison with the ACE Programme Lead/ attendance at cluster group meetings**

The Clinical Lead and/or the Project Manager regularly attended cluster group meetings, which they reported finding very useful, particularly as a mechanism for sharing issues with others trying to implement similar pathways. The Project Manager also met regularly with the ACE programme Manager who provided support and often acted as a “critical friend”:

“He’s asked me why I think the way I think and asking for the rationale behind the processes that we’ve implemented. Most of the time he is very supportive of what we are doing but then he also comes up with names of people, suggests I go and see people on different projects so I can get another perspective. But he also gives his perspective and throws it in the pot for me to mull over and it’s a fairly reflective process”

Project Manager


**Interpretation**

The majority of people interviewed felt that the pathway was a good thing for patients and that direct access from primary care had worked well with the pathway becoming established and starting to become embedded.

There was support from the Croydon Clinical Commissioning Group in principle for this initiative but how that converted to practical help and support is unclear.

It is also unclear as to how much buy in or support came from senior levels and middle management within Croydon Health Services NHS Trust. A number of interviews referred to problems being escalated and executive level management being on board to address some fundamental issues, such as information systems not being fit for purpose. We are unable to comment on the effectiveness of these interventions as the issues were “work in progress” and remained unresolved at the time of the final interviews.

With hindsight it may have been helpful to get a board level champion engaged during the planning stages of this project to ensure senior level ownership.

**B.1.3.5 Leadership (Me)**

**Context and Mechanisms**

This was an example of single clinically-led leadership initiating the project with limited senior management ownership.

The initiation and overall leadership of this project came primarily from the Clinical lead and Project Manager. Soon after the appointment of the Project Manager, a PID (Project Initiation Document) was developed, stakeholder opinions were sought and a Steering Group was established. However, ownership of the project at senior management level appeared limited.

**Characteristics of mechanisms and outcomes**

The Clinical Lead did not have a formal management model in mind to support the implementation of this project. Neither did the Project Manager, although she did have extensive Project Management experience in the NHS.

The Clinical Lead and Project Manager were very “hands on” dealing with operational issues as they arose and taking some more strategic but less urgent issues to the Steering Group for resolution. On a practical level this approach worked very well:

“*The project is running on his leadership (Clinical Lead), and he’s very, very engaged, he’s taken it upon himself to run the clinics himself to ensure that all the teething problems are eased . . . . . . . So as we are going through each patient, we are picking up what is running well and what isn’t. So we are correcting as we go along. . . . . . . . So he’s doing it himself with a view that he would hand it over to a junior*”

Project Manager
By the time the final interviews were conducted there was evidence that the clinical delivery of this work had been devolved to Specialist Registrars, which was an important step to ensure long term sustainability of the pathway.

The role of the Project Manager was highly valued by the majority of those interviewed:

“I don’t know what we would have done without her she has just got on and sorted things out and then told me about it later”

Service Manager

“YYY (Project Manager) has been a great success and a great help”

Lead Clinician

There was also some degree of concern relating to the fixed term nature of the Project Manager’s post and capacity to address ongoing issues as the pathway continues to become embedded:

“I honestly don’t know what’s going to happen once YYY leaves”

Lead Clinician

“I would have liked her (Project Manager) to stay a bit longer but she was keen to go. I don’t know where the capacity will come from to deal with problems”

Service Manager

One area which proved problematic from a leadership perspective was the leads’ ability to influence the IT department despite them reportedly having Board Level support. At the time of the final set of interviews it was reported that there had been limited success in this arena and that this was still work in progress

**Interpretation**

Leadership has been an important factor in getting this pathway established and the project relied heavily on the Project Manager and Clinical Lead to implement and maintain the pathway. There are risks to the sustainability of the pathway now that the Project Manager has left the organization.

The part time, fixed term nature of the Project Manager post and the amount and complexity of the work did create considerable pressure for the post holder and as a result she was reluctant to stay beyond the timescale specified within her contract. Despite this, the Project Manager’s ability to adapt in different organizational settings and circumstances was evidenced throughout the case study interviews. Success in engaging stakeholders from primary and secondary care and the CCG was often a result of the tenacity of the Project Manager. She adapted quickly to the role and was well accepted, in part because she was an experienced Project Manager with excellent interpersonal skills. The clinical support provided by the Clinical Lead also reinforced her credibility; perhaps what was lacking was local intelligence relating to personalities and behaviours of individuals who were key stakeholders, which may have assisted her in identifying the most effective strategies to manage
particular situations. This lack of local intelligence undoubtedly resulted in wasted time and a number of ineffective interactions.

Due to the tight timescales identified for the project and the pressure from the CCG and acute trust to be seen to achieve tangible outcomes, the post holders had to “hit the ground running” once appointed. This meant that for the Project Manager the focus was on deliverables and perhaps the project might have benefited from more clarity around the scope of influence of the role and how to liaise directly with more senior levels particularly within secondary care. Had this been done at the outset it may have been easier to negotiate some of the internal politics of the organization and escalate problems at an early stage.

**B.1.3.6 Funding (Me)**

**Context and Mechanisms**

ACE provided funding for the Project Manager role and the Data analyst to support the project.

**Characteristics of mechanisms and outcomes**

The Project Manager commenced her role in April 2015, on a one year, fixed term contract. In that time she quickly established herself and got the pathway operationalized and on the way to being embedded.

The Data analyst was funded mid-way through the project and did a significant amount of work to develop a comprehensive manual database whilst overarching information systems issues were being addressed. She also spent time trawling for missing data and working with the Project Manager and others to ensure data was collected using agreed systems and processes.

The Data Analyst will continue to monitor the pathway, provide low level project management support and provide relevant reports to the steering group in the medium term whilst the pathway moves towards normalization.

**Interpretation**

It is unlikely that the pathway would have been implemented as quickly had the Project Manager not been appointed, due to existing pressures on the Clinical Lead.

The appointment of the Data Analyst proved useful in gathering evidence relating to the efficacy of the pathway in an area where inadequate information systems exist. Without external funding these posts would not have existed.
B.1.3.7 CQUINS (Mf)

Context and Mechanisms
CQUIN (Commissioning for Quality and Innovation) payments are meant to encourage care providers to share and continually improve the way in which care is delivered. CQUINs enable commissioners to reward excellence by linking a proportion of English healthcare providers’ income to the achievement of locally set targets.

A CQUIN was developed “To enable appropriate diagnostics, ‘straight to test’ for suspected cancer (enabling 28 day cancer target for patients to have cancer confirmed or excluded) and a reduction of routine waits from 6 weeks to 3-4 weeks”

Characteristics of mechanisms and outcomes
For 2015/16 the wait was reduced to 4 weeks for patients aged 40-60 years. The target waiting times for endoscopy for 2016/17 are being monitored on a quarterly basis, however endoscopy capacity and therefore waiting times are becoming an increasing pressure.

Mechanisms in place to address this including weekend and evening working as well as the possible opening of another endoscopy suite in October 2016 (still to be confirmed).

Interpretation
The CQUIN developed by the CCG was patient focused and relevant to this pathway, however, it did not take into account the increasing demands on diagnostic services and the need to proactively increase capacity.

B.1.3.8 Addressing Information systems (Mg)

Context and Mechanisms
There was a lack of co-ordination of information-sharing systems and processes between primary and secondary care. Information systems within primary and secondary care are not compatible; as a result the commissioners have struggled to get meaningful data in relation to the pathway and in particular, data relating to activity in terms of Direct Access referrals and Outpatient referrals.

For example, it became evident relatively early in the project that it was not possible for the existing secondary care system to deal with Direct Access referrals separately from other endoscopy referrals. Furthermore, patient records were sometimes incomplete due to endoscopy staff not completing all of the required fields on the IT system. In order to resolve these issues, there were regular discussions both within the Steering Group and between the individuals responsible, and a project Data Analyst was ultimately appointed.
Characteristics of mechanisms and outcomes

The hospital IT department were involved in the discussions with the steering group about these system issues at a relatively early stage, though little was resolved, and lack of progress was extremely frustrating for the CCG and Project Leads. The issues were therefore escalated to Board level and whilst not resolved at the time of the final set of interviews commitment to addressing the issues had been given.

In order achieve greater completeness and provide data whilst the system problems were being resolved a manual database was developed for management purposes. This was also completed retrospectively, so that all patients past and current were captured. The Data Analyst also started producing regular reports for the Steering Group.

Interpretation

The provision of accurate data has been a long standing problem for the project and made any meaningful local quantitative evaluation difficult. A review of the information systems prior to commencing the project would have been useful and more senior involvement from the IT department at an early stage may have facilitated a more timely resolution of the issues.

B.1.4 Conclusions

Some of the outcomes specified in the CMO table (figure 2) were successfully achieved and will be sustainable; for others success and sustainability is less clear:

01. Faster route to diagnosis; informants reported that those patients who would previously have been placed on a non-urgent pathway were being seen more quickly. However due to increasing pressures on endoscopy services it is unclear as to whether this improvement can be sustained.

02. Diagnosis and treatment of diseases other than cancer- this outcome has been achieved, with many patients given a diagnosis, treated and discharged on the same day as the test. Those with more complex problems are referred elsewhere as appropriate.

03. Patient satisfaction- informants reported that the vast majority of patients surveyed following their endoscopy procedure were very happy with the service. We did not see any quantitative results from this survey.

04. Meeting targets – analysis of the interviews indicated that there is no evidence of cancer waiting time targets not being met as a result of implementing this pathway, patients with suspected cancer are upgraded to the 2WW pathway. In addition, initial CQUIN targets requiring patients to have cancer confirmed or excluded within 28 days have been met.

05. Improved quality of referrals - there is anecdotal evidence that the completeness of referrals has improved substantially. Initially a proportion of referral forms had to
be returned to the GP because they were incomplete; this decreased gradually over the project period.

O6. Streamlined pathway - the new ‘straight to test’ pathway has been streamlined for patients with rectal bleeding who fulfil the referral criteria, however other bowel pathways are still in existence though they are currently under review.

O7. Learning from project to influence future development – learning from the project has been widely shared internally and with London Cancer, also with the ACE Colorectal Pathway Cluster Group. We do not have any evidence of how other sites have utilised this learning.

O8. Sustainability – the pathway is embedded and well utilised, however there is a risk to its sustainability due to the unresolved capacity issues in endoscopy.

O9. Understanding the changes needed to IT systems to meet primary and secondary care information requirements – this issue was only really being understood towards the end of the project and when the final interviews took place there was still significant work needed to address the identified problems.

Applying a Normalisation Process Theory framework to our findings, we conclude that the service has been normalised (become part of the working practice of GPs) in primary care but that normalisation in secondary care and the commissioning services was not yet established. This represents a threat to the sustainability of the service (table 4)


<table>
<thead>
<tr>
<th>Coherence</th>
<th>Cognitive participation</th>
<th>Collective action</th>
<th>Reflexive monitoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the work?</td>
<td>Who does the work?</td>
<td>How does the work get done?</td>
<td>How is the work understood?</td>
</tr>
<tr>
<td>Systematic explanation of mechanisms and components at work</td>
<td>The CCG and GP practices recognised it as being similar to an extension to existing pathways. However, multiple colorectal pathways still exist. GPs understood the mechanisms of referral and how it linked with the ‘straight to test’ service. No real understanding about requirements for endoscopy capacity</td>
<td>GPs do the initial assessment, consenting and prescribing bowel prep. Endoscopists carry out the intervention</td>
<td>Working closely with the Project Manager has helped with appraisal of systems and processes by primary and secondary care staff</td>
</tr>
<tr>
<td>Knowledge about the sources and operation of investments at work</td>
<td>Value of the intervention was promoted by proponents of the service, by appeals to ‘do the right thing’ and promotion of potential financial incentive. There was consensus that the intervention was worthwhile from a patient perspective</td>
<td>Training was provided in relation to the pathway and how to complete the referral forms. Ongoing support was provided by the Project Manager</td>
<td>There is reasonably good understanding of factors affecting the pathway but these are not across all stakeholders, there are implications in terms of having sufficient capacity within secondary care, still a number of commissioning issues to be addressed</td>
</tr>
</tbody>
</table>

| Training was provided in relation to the pathway and how to complete the referral forms. Ongoing support was provided by the Project Manager | | | Risk now PM no longer in post. |

<p>| Table 4 Factors associated with the normalisation of Croydon Health Service NHS trust and Croydon CCG Direct Access Service for colorectal symptoms |</p>
<table>
<thead>
<tr>
<th>Core questions</th>
<th>How is a practice conceptualised by participants? Viewed positively though by those referring in and those delivering the service</th>
</tr>
</thead>
<tbody>
<tr>
<td>How does it hold together in action? GPs referring to service. Demand currently outweighs capacity. Activity also appearing to rise in outpatients which is prompting questions about why this is the case from commissioners</td>
<td></td>
</tr>
<tr>
<td>How do participants come to engage with a practice? The idea that the pathway was better for patients encouraged initial engagement. More sustained engagement due to education and training of GPs and ongoing support provided to practices. Concerns over sustainability now PM no longer in post</td>
<td></td>
</tr>
<tr>
<td>How do they decide on engagement and the purposes that it serves? Discussions around value to the patient, value to the GP practice. Consideration of additional workload and subsequent impact on capacity. Project driven by lead clinician and PM – lack of ownership seen elsewhere in secondary care.</td>
<td></td>
</tr>
<tr>
<td>How do participants enact a practice? Follow protocol. Enlist support from Project Manager. Risk now PM no longer in post</td>
<td></td>
</tr>
<tr>
<td>How are their activities structured and constrained? GPs are responsible for assessment, consent, referral and prescribing bowel prep. CRESS are responsible for monitoring referral form data, Secondary care admin for booking the patient. Endoscopy for Management. PM for support across the pathway. Results go back to the GP for management</td>
<td></td>
</tr>
<tr>
<td>How do participants appraise a practice? Appraisal and feedback encouraged via the steering group and regular contact with the Project Manager also via the activity reports Steering group continues with a wider remit, there is a risk that the project loses its current priority status.</td>
<td></td>
</tr>
<tr>
<td>What are its effects of appraisal? Appraisal has resulted in changes to systems and processes to support the pathway (SOP). It has also led to a shared understanding that data availability has been poor and that needs addressing Appraisal has also led to changes in the steering group remit</td>
<td></td>
</tr>
</tbody>
</table>
B.2 Wrightington, Wigan and Leigh NHS Foundation Trust Straight to Test Endoscopy Service for Suspected Colorectal Cancer Referrals

The following case study describes the processes involved in implementation of a Straight to Test Endoscopy Service for Suspected Colorectal Cancer Referrals as part of the ACE programme. The service is continuing and this qualitative evaluation covers the period to April 2016.

B.2.1 Introduction and background

Wrightington, Wigan and Leigh NHS Foundation Trust are a large acute trust providing services in Lancashire. It operates from five sites; three hospitals, an outpatient centre and an ophthalmology unit.

The District General Hospital in Wigan (known as the Royal Albert Edward Infirmary) is a redeveloped modern District General Hospital with 513 beds providing a base for emergency and acute medical care. It has a range of both inpatient and outpatient services providing for a population of approximately 350,000. Prior to implementing the ACE project the Trust received approximately 850 suspected colorectal cancer referrals per annum equating to approximately 70 per month.

B.2.1.1 Aims and Objectives

To develop a “Straight to Test” endoscopy service for suspected colorectal cancer referrals.

B.2.1.2 Ace Model

The proposed service involved consultant led triage of urgent suspected cancer (Two week wait, 2WW) colorectal cancer referrals with the aim of patients being booked directly to endoscopy for their diagnostic procedure, thus eliminating the need for an initial outpatient consultation.

The service was intended to be a one stop facility that would exclude cancer as a cause of symptoms but also allow sufficient clinical time for further evaluation of symptoms and treatment where appropriate.

Initially one consultant would be responsible for triaging the patients and 3 consultant lists would be available for service delivery with 4-6 patients being seen in each session. This would be a redirection of resources, and would not require additional capacity.

Referrals are made via the 2WW route with the GP using the standard suspected colorectal cancer urgent referral proforma. GPs are required to include patient’s symptoms, details of their clinical examination, including rectal examination, and any co-morbidities. The completed proforma is then emailed to the Trust Central Booking Team for registration onto the Patient Administration System (PAS) system. On receipt of the referral the booking team then emails the referral to a dedicated Straight to Test email address for triage by the Lead Clinician.
The booking team are informed of the result of triage: either Straight to Test or Outpatient appointment and an appointment is arranged.

Inclusion criteria (based on NICE guidance):

- Rectal bleed with or without anal symptoms and no change in bowel habit for 6 weeks or more.
- Rectal bleed with change in bowel habit for 6 weeks or more
- Change in bowel habit for 6 weeks or more without rectal bleeding
- Unexplained iron deficiency

Exclusion criteria:

- Recent MI within 6 months
- Home oxygen
- Immobile or very frail
- Bowel obstruction
- Presence of ileostomy
- Palpable rectal mass/perianal patient and inability to perform PR

Figure 3 Pathway for Wrightington, Wigan and Leigh NHS Foundation Trust straight to test endoscopy service

**B.2.1.3 Project Scope**

This was a 1 year pilot period with the intention of mainstreaming the pathway thereafter.
B.2.1.4 Implementation

The project had a Clinical Lead, who was a Colorectal Surgeon, supported by the Service Improvement Manager for Cancer Services. The project commenced in March 2015. A data analyst was appointed in Autumn 2015.

B.2.2 Methodology

As discussed in the methodology section of this paper the qualitative evaluation of the ACE programme draws on the principles of realist evaluation (Pawson and Tilley, 1997) to develop a contextualised account of the way in which change emerges. See section 2.1 for details of realist methodology. For the purposes of this case study, a total of 11 1:1 interviews with key informants were carried out.

Analysis of the interviews resulted in the development of a Context, Mechanisms and Outcomes (CMO) model (figure 4)

The CMO model considers the contexts, mechanisms and outcomes that were apparent in the implementation of the initiative. Each of the key mechanisms is considered in turn within the case study.

Normalisation Process Theory (NPT) provides the theoretical basis for understanding how the initiative is understood, implemented and embedded into normal practice. NPT considers four areas; coherence, cognitive participation, collective action, and reflexive monitoring. See section 2.2 for details. Each of these areas are considered in turn in table 5.

![CMO model for Wrightington, Wigan and Leigh NHS Foundation Trust straight to test endoscopy service](image-url)
N.B. We do not specifically discuss the second cluster M1-M4 because they are components of the mechanisms discussed Ma-Md

B.2.3 Contexts, Mechanisms and Outcomes (CMO)

B.2.3.1 Service/pathway design (Ma)

Context and Mechanisms

A new pathway, the detail of which has been described earlier was developed by the lead clinician and Service Improvement Manager and implemented. The pathway provided triaged access to a Straight to Test endoscopy service for patients with suspected colorectal cancer.

The pathway was led and implemented by a Colorectal Surgeon who was committed to service improvement and who was enthusiastic about improving services for colorectal patients. She was supported by an experienced Service Improvement Manager for Cancer Services.

They had attempted to implement a similar pathway in the past but had encountered resistance from surgical colleagues. This pathway had been in development for approximately two years.

“So we have been planning it for about two years. It’s taken two years to get through the CCG (planning processes)”

Lead Clinician

Characteristics of mechanisms and outcomes

A business case was developed which cited participation in the ACE project as a supporting factor in the case for change. This was driven by the lead clinician and Service Improvement Manager, with support from others within the CCG. They also consulted Tameside Hospital to see what could be learned from them, as they had already successfully implemented a straight to test pathway:

“We’ve implemented the model that we looked at in Tameside”

Service Improvement Manager – Cancer Services

The business case was supported and approved by Wrightington, Wigan and Leigh NHS Foundation Trust and Wigan Borough CCG. A SOP for the pathway with triage criteria were developed prior to the service going live. The referral proforma required some redesign in order to fit with the new pathway. GPs were consulted regarding the new proforma and initially there was some resistance to the changes proposed. However these were resolved with discussion.

Some minor practical issues emerged in the initial stages of the project:

“I set the dedicated in-box up for the consultant. The consultant had a very large inbox and couldn’t send any emails, so on the first day she couldn’t respond electronically and was using her phone, and I didn’t really think that was good, I think
it would have been better if we had been involved in the planning rather than waiting until it went operational.”

Admin Manager

Standard letters were also developed to support the service. These subsequently had to be modified in line with a Trust-wide quality champions project that was focused on reducing the number of patient letters and improving the quality of those that were retained.

When the project started the pre-endoscopy bowel prep was sent out to patients from the endoscopy department with instructions regarding how to take it. Part way through the pilot period, guidance on issuing bowel prep changed to require each bowel prep to be prescribed by a consultant. This has proved challenging to comply with and the process being followed by the time of the final set of interviews was that the clinician triaging the referral would prescribe the prep, which the patient would then have to collect from the hospital pharmacy. This has introduced an extra inconvenience for patients. The process of providing patients with bowel prep is currently under review.

The pathway has been well accepted by the GPs, with referral rates being consistently high (ranging from 77 to 132 per month, with an average of 115.6 per month). There have been 1388 referrals in the period from April 2015 to March 2016, with 799 (57.6%) going straight to test

“I’ve noticed the numbers have gone up quite significantly . . . . now were hitting 120 (referrals per month). So maybe the GPs have got confidence in it”

Service Improvement Manager for Cancer Services

“Feedback has been good, they (GPs) like the pathway”

Lead Clinician

Anecdotally, patients also like the pathway:

“Well, the patients you know, they love it because they’ll come and they have one test and I can tell the majority they haven’t got bowel cancer and we never have to see them again. And it’s the way I do it. So I say you have been sent here to make sure you haven’t got bowel cancer. So even if they have bits and pieces and they have symptoms, I say to them the symptoms are not to do with bowel cancer and I tell them what I think the symptoms are and discharge them and they’re happy”

Lead Clinician

There has however been no formal evaluation of patient satisfaction in relation to this pathway, though this is an aspiration for the future.

At the time of the final round of interviews, the pilot period had ended and the pathway was continuing as a mainstream service.

Interpretation

With hindsight it may have been better to involve the Admin Manager in the planning stages of the project rather than waiting until implementation. However it
must be noted that once problems were identified, they were quickly and proactively managed.

**B.2.3.2 Evaluation of capacity: staffing, time (Mb)**

**Context and Mechanisms**

Initially, all of the project development and implementation work was conducted by 2 key individuals; the Clinical Lead and the Service Improvement Manager for Cancer Services. This work was in addition to their existing workload.

Prior to implementation the Service Improvement Manager for Cancer Services did some endoscopy capacity modelling:

“The national team had a capacity tool that I used, I put all the referrals into that, you know, that broke down into weekly referrals and charted them all. So I definitely found that useful in the beginning, we could probably do with revisiting that really”

Service Improvement Manager for Cancer Services

**Characteristics of mechanisms and outcomes**

Despite the modelling work there were a few problems around the lead clinician’s capacity:

“We’ve had a few teething issues about capacity, obviously its clinician led so triage falls heavily on XX”

Service Improvement Manager for Cancer Services

As the project developed there were also clinic/endoscopy capacity issues, caused by clinicians cancelling clinics due to annual leave. In a bid to address this, the Lead Clinician was actively lobbying her colleagues to put on extra clinics when they returned in order to regain the lost capacity:

“Yes capacity has been an issue but XX has been asking them to do extra to make up for lost lists, that seems to be working”

Data analyst

The Service Improvement Manager- Cancer Services was responsible for the non-clinical elements of the project, however these responsibilities were in addition to those related to her substantive role:

“I’ve fallen a little bit distant from the project because of other work streams that I’ve got going on, so this is why when I’ve spoken to BB (the ACE cluster lead) I’ve said I’ve needed some help, I needed a project person to help me with it to collect all the data, to make sure all the actions that we agreed were implemented, to keep working with the CCG and GPs as well as working with endoscopy, so I really, so BB awarded me some money to get a project person in.”

Service Improvement Manager for Cancer Services
Interpretation

Capacity issues can occur when staff are required to take on roles in addition to their day to day responsibilities. Capacity modelling prior to the commencement of a project can allow some of these potential issues to be identified. However, even with the modelling that was done, capacity problems arose and needed to be dealt with, sometimes on an ad hoc basis. More detailed modelling may have avoided this.

B.2.3.3 Connections and communication between professionals (Mc)

Context and Mechanisms

Regular performance meetings were held between the Trust and the CCG involving representatives from the directorate, managers, clinical leads, admin managers and data analysts

Training for GPs on the purpose and use of the pathway was also provided.

Characteristics of mechanisms and outcomes

Weekly performance meetings have been the mechanism for reviewing progress, tracking patients and raising and addressing issues, these have been effective in maintaining engagement as well as getting people more closely involved in the project. They have also been a means of ensuring that the project remains high on the surgical directorate’s agenda:

“We do have weekly PTL meetings (performance meetings), so all he patients are being tracked anyway and so if it (waiting time) was going up the surgical management division would be able to pick it up. So I think everyone’s got more closely involved in the monitoring”

Service Improvement Manager for Cancer Services

Communication with the CCG started at an early stage and there were regular meetings in the planning period. This ensured their initial engagement and continued support.

Communication with the GPs has been effective and sustained and the number of referrals is evidence of their awareness of the pathway. Of the 1388 referrals received, only 8 were judged to not meet the referral criteria, suggesting that GPs had a clear understanding of the pathway.

Learning from the project has been shared at a national level through poster presentations at the Association of Colooproctology conference 2016.

Interpretation

Early communication and engagement is essential in the planning stages of the project as it helps ensure strategic level buy in and ensures a shared vision for the pathway. Performance meetings enabled communication between the professionals involved in the planning, implementation, delivery and use of the pathway (see Ma
for more detail). GP education appears to have been successful in developing awareness and correct use of the referral criteria.

**B.2.3.4 Analysis of data (Md)**

**Context and Mechanisms**

Data collection was recognised as a key component of the pilot to evaluate its effectiveness. However it became apparent that the Service Improvement Lead for Cancer Services did not have sufficient capacity to take on data analysis alongside her other responsibilities.

**Characteristics of mechanisms and outcomes**

The Service Improvement Lead for Cancer Services approached the ACE Cluster Lead for some additional funding for a data analyst:

“*I needed a project person to help me with it to collect all the data*”

Service Improvement Manager for Cancer Services

Funding was subsequently provided by ACE and the post was filled in Autumn 2015. The role was viewed as being invaluable, with additional work being carried out which would not have been possible without her:

“The lady that was appointed is really, really good. She’s very good at data collection and analysis. We’ve done an audit and she’s helped with that. We’re presenting a poster at the Association of Coloproctology, which I’m very proud of, so it’s been a huge help with her collecting data”

Lead Clinician

The data analyst was able to articulate some of the areas which routine data collection could evidence:

“I think the biggest success has been the number of patients who get treated quickly. You know, the triage straight to test, some of them get seen very quickly, obviously some still need to go to clinic first. That process is taking on average nine days. A lot of them are being discharged on the day. They’re going away with peace of mind, it’s not cancer, it’s you know a non-cancer diagnosis; maybe polyps or diverticular disease. But they are going away with peace of mind in such a short timescale”

Data Analyst

Data are presented at the weekly performance meetings and a monthly “Data Highlights” report is also compiled by the data analyst, this includes data relating to the numbers of referrals, a breakdown of those going straight to test and those being seen in outpatients, the average wait in days, investigations carried out for the straight to test patients and outpatient appointment patients, numbers of discharges on the day of test and the reported period of symptoms. Additional work has also been conducted to look at numbers of inappropriate referrals (this was anecdotally reported as being very low). There are also plans to look specifically at referrals of patients aged over 80 years.
Interpretation

Evaluation and data collection was deemed to be a priority for this project to provide monitoring and evaluation of its effectiveness. However due to capacity issues of the Service Improvement Manager it is unlikely that the analysis and associated understanding of the data would have occurred if the additional resource of the Data Analyst had not been sought.

B.2.4 Conclusion

Some of the outcomes specified in the CMO table (figure 4) were successfully achieved and will be sustainable; for others success and sustainability is less clear:

O1. Faster route to diagnosis – Informants reported that for the straight to test patients the diagnosis is quicker, this is particularly noticeable in those with non-cancer diagnosis who are discharged on the day.

O2. Understanding of staffing/capacity needs – the use of the toolkit prior to the pilot starting was useful in identifying initial capacity requirements. Despite modelling, problems arose with consultant capacity and constant review of activity data is providing ongoing understanding of staffing/capacity needs.

O3. Patient satisfaction – there is anecdotal evidence of patient satisfaction, notably with receiving an ‘all clear’ on the same day, though no formal evaluation has been conducted.

O4. Smaller waiting lists in other clinics – Data to show a corresponding reduction in waiting lists for other clinics has not yet been produced.

O5. Roll out to other departments – interviewees have provided anecdotal evidence of interest in the pathway from other clinical areas within the Trust and the team have been proactive in promoting this model. In addition learning has been shared on a wider basis via a poster which was presented at the Association of Coloproctology meeting where the model was shared and feedback was positive.

O6. One-stop diagnosis and treatment of diseases other than cancer – there is evidence from the interviews that one-stop diagnosis and treatment has occurred when appropriate. There are examples of patients who have not required clinical intervention being reassured that they don’t have cancer and being discharged on the same day and of patients whose problem required a simple procedure, such as banding of haemorrhoids, being treated and discharged on the same day.

O7. Sustainability of service – the service appears to be sustainable, many processes have been normalised (see table 5) and the service has now been mainstreamed.

Applying a Normalisation Process Theory framework to our findings, we conclude that the service has been normalised (see table 5). We observed that Cognitive participation was enhanced as staff could see both immediate and longer-term benefits to patients and practice. High levels of cognitive participation then helped to engage staff in collective action. Reflexive monitoring was enabled via the
performance meetings and provision of regular feedback relating to updating on
systems and process development and activity. The monitoring and reporting of data
was made easier by the appointment of the Data Analyst who enabled the provision
of accurate and timely data.

The pathway has been adopted and is well on its way to being normalized. Reflexive
monitoring has resulted in small changes to the Standard Operating Procedure and
protocol.

<p>| Table 5 - Factors associated with the normalisation of Wrightington, Wigan and Leigh NHS Foundation Trust Straight to Test Endoscopy Service for Suspected Colorectal Cancer Referrals |
|---|---|---|---|
| Coherence |
| Systematic explanation of mechanisms and components at work |
| The Trust and local CCG recognised a need to manage these patients differently. Regular feedback from the Lead Clinician and the Service Improvement Manager for Cancer Services have reinforced the mechanisms of the process |
| Cognitive participation. |
| Who does the work? |
| GPs use the colorectal 2ww proforma to refer. The Lead Clinician triages the referral. Patients are allocated to go straight to test or outpatients. Endoscopists carry out the intervention |
| Collective action |
| How does the work get done? |
| Training was provided in relation to the pathway and how to refer. Ongoing support was provided by the Service Improvement Manager for Cancer Services |
| Reflexive monitoring |
| How is the work understood? |
| The Lead Clinician, Service Improvement Manager for Cancer Services and Data Analyst work closely to appraise f systems and processes. |
| Knowledge about the sources and operation of investments at work |
| GPs understood the mechanisms of referral and how it linked with the straight to test service. |
| Capacity modelling was done prior to implementing the pilot |
| Core questions |
| How is a practice conceptualised by participants? |
| Viewed positively though by those |
| How do participants come to engage with a practice? |
| The idea that the pathway was better for patients |
| How do participants enact a practice? |
| Follow protocol. |
| How do participants appraise a practice? |
| Appraisal and feedback happens informally between the Lead Clinician, |</p>
<table>
<thead>
<tr>
<th>How does it hold together in action?</th>
<th>How do they decide on engagement and the purposes that it serves?</th>
<th>How are their activities structured and constrained?</th>
</tr>
</thead>
<tbody>
<tr>
<td>GPs referring to service. Capacity only an issue when Consultants on leave, plans in place to address missing capacity.</td>
<td>Discussions around value to the patient, value to the GP practice. Consideration of additional workload and subsequent impact on capacity. Project driven by lead clinician and Service Improvement Manager for Cancer Services</td>
<td>GPs are responsible for, referral, the Lead Clinician for triaging and prescribing bowel prep secondary care admin for booking the patient. Clinicians in Endoscopy for diagnosis and where appropriate management and or discharge.</td>
</tr>
<tr>
<td>Service Improvement Manager for Cancer Services and Data Analyst who work closely to appraise the pathway. Monthly data reports are also complied and shared and the weekly performance meeting provided an opportunity to share and manage issues.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix C Proactive Lung Cluster Case Studies

C.1 Liverpool Healthy Lung Project

Nationally lung cancer causes nearly a third of cancer deaths with two out of three patients diagnosed with lung cancer dying within 1 year. Survival for lung cancer is the second lowest out of 20 common cancers in England and Wales.

Within the proactive lung cluster there were six projects focusing on the identification (or case finding) of individuals at high risk of developing lung cancer. 1 site participated in this qualitative evaluation, the Liverpool Healthy Lung Project (LHLPP).

The following case study describes the processes involved in implementation of the project, from April 2015 to September 2016, although the project is ongoing.

C.1.1 Introduction and background

Reducing the incidence of lung cancer and improving cancer outcomes are public health priorities for Liverpool. The number of new lung cancer cases is significantly higher than the national average and the city has one of the highest mortality rates from lung cancer in England. In addition many patients also present with a late stage disease. However, Liverpool has good surgical and oncological services for lung cancer, demonstrated by having one of the highest tumour biopsy and lung resection rates accompanied by one of the highest five year survival rates in England and Wales.

The ACE project was a collaborative project involving Liverpool CCG, senior cancer and clinical leads from Liverpool Heart and Chest Hospital, Aintree and the Royal Liverpool and Broadgreen Hospitals, Liverpool Public Health and the University of Liverpool.
The project was actually in the planning stages for approximately 18 months prior to going live. When the leadership team saw the call for ACE projects they felt their project fulfilled the ACE criteria and that there was an opportunity to secure funding for a full-time Project Manager to support the implementation process.

**C.1.1.1 Aims and Objectives**

The aim of the LHLP was to reduce the city’s mortality rate from lung cancer and to narrow the health inequalities with the rest of England. They aimed to do this through a range of pro-active measures targeted at people at high risk of lung cancer. The objectives of the LHLP were to:

- Increase knowledge and understanding in communities
- Promote positive messages around lung health
- Tackle the fear and fatalism surrounding lung cancer
- Identify people at higher risk of lung cancer (the ‘case finding’ programme) and offer these patients an intervention to reduce risk. For some people, this would include the offer of low dose non-enhanced CT
- Use the lung health check to engage people about lung health (the ‘teachable moment’)
- Signpost patients to lifestyle support services where appropriate
- Via the case finding programme, identify a number of lung cancers at an earlier stage, before symptoms develop, to enable early treatment and improve patient outcomes.
- Identify previously undiagnosed COPD (there are currently an estimated 6,000 people with undiagnosed COPD in Liverpool).
- Contribute to the developing national policy and evidence around the early diagnosis of lung cancer, via participation in the ACE programme.

**C.1.1.2 Ace Model**

The objectives of the Liverpool Healthy Lung project would be addressed through a two phase approach:

**Phase 1** – Healthy Lung Community Events aimed at increasing awareness of respiratory health, promoting positive messages around lung health and encouraging participation in Phase 2 of the project. Phase 1 targeted Liverpool residents in four identified pilot neighbourhoods; Picton, Speke, Everton and Norris Green.

**Phase 2** – Invite people living in these 4 neighbourhoods who were at higher risk of developing lung cancer to attend General Practice for a lung health check. High risk was defined by the following criteria:

1. Aged 58-70 years (mandatory criteria) and
2. Ever smoked or
3. COPD diagnosis

Phase 2 exclusion criteria:
- Diagnosis of lung cancer
- Terminally ill
- GP Practice deems unsuitable for invitation

The lung health check involved a calculation of the person’s risk of developing lung cancer over the next five years (My Lung Risk, Liverpool Lung Project, University of Liverpool, 2014). Those with a risk >5% were offered a low dose non-enhanced CT scan. In the first year Liverpool intended to pilot this approach in specific geographical areas that had been selected by lung cancer incidence/mortality and deprivation.

C.1.1.3 Project Scope

Assuming successful evaluation of Year 1 (due March 2017), it was planned to extend the programme citywide, although the timescale for this is still to be confirmed.

A Project Manager was initially appointed for one year from April 2015; this role has subsequently been extended until the end of March 2017.

An externally commissioned evaluation is due to report after March 2017.

C.1.1.4 Implementation

A project Manager was appointed to support the delivery of this work programme.

In addition, a steering group including key stakeholders was established. In order to provide the project manager with support seven initial work streams were identified. Each work stream had a named lead (appointed by the Steering Group). The work streams reported monthly in the first instance to the Healthy Lung Steering Group, who made recommendations concerning the future realisation of the aims, objectives and benefits associated with the Liverpool Healthy Lung Project.

- Governance
- Outcomes & Evaluation
- Information Management and Technical (IT)
- Information Governance (IG)
- Finance, Contracts & Procurement
- Engagement & Communications
- Service Delivery (including clinical pathways)

The Steering Group was also responsible for the management and monitoring of the project, which meant that it controlled the realisation of the project at the strategic level, verified the project’s coherence with established aims, and kept it within established frames such as range, costs, risks and deadlines. In addition the group was also responsible for the governance and performance management of the project, monitoring key performance indicators. Close oversight from the group meant that any changes to the project were first presented to and had to be accepted by the steering group.
The steering group was responsible for creating working groups and choosing expert, with whom they would work to realize the project.

C.1.2 Methodology

The qualitative evaluation of the ACE programme draws on the principles of realist evaluation (Pawson and Tilley, 1997) to develop a contextualised account of the way in which change emerges. See section 2.1 for details of realist methodology. For the purposes of this case study, a total of 23 1:1 interviews with key informants were carried out.

Analysis of the interviews resulted in the development of a Context, Mechanisms and Outcomes (CMO) model (figure 5)

The CMO model considers the contexts, mechanisms and outcomes that were apparent in the implementation of the initiative. Each of the key mechanisms is considered in turn within the case study.

Normalisation Process Theory (NPT) provides the theoretical basis for understanding how the initiative is understood, implemented and embedded into normal practice. NPT considers four areas; coherence, cognitive participation, collective action, and reflexive monitoring. See section 2.2 for details. Each of these areas are considered in turn in table 6.

![CMO model for Liverpool Healthy Lung project](image-url)

(N.B. We do not specifically discuss the second cluster M1-M6 because they are components of the mechanisms discussed Ma-Mf)
C.1.3 Contexts, Mechanisms and Outcomes (CMO)

C.1.3.1 Project Management (Mn)

Context and mechanisms
The initial business case was developed by the steering group and led by the CCG Cancer Clinical Lead and Cancer Transforming Services Manager. A Project Manager was appointed initially on a one year fixed term basis. She commenced her role in April 2015 and was funded by ACE. Funding was extended by the CCG until March 2017 but is an ongoing issue requiring resolution after March 2017. The intention is for the LHLP to be a three year project.

Characteristics of mechanisms and outcomes
The Project Manager was instrumental in ensuring that the project was realised, she was responsible for dealing with operational and strategic issues. She has also been the key point of contact for stakeholders, supporting and liaising with them on a daily basis.

The Project Manager was trained in PRINCE2 methodology and this was clearly evidenced by the planning processes which were implemented to deliver the project. For example, she developed systems and processes for monitoring progress and mechanisms for reporting issues and risks back to the steering group.

The post holder was highly valued by colleagues on the steering group:

“I think we have really valued the role and the skills she (Project Manager) brings which we benefited from . . . . XXX (the Project Manager) is obviously extremely competent but I think it has been essential that she had devoted her whole time to this project. So I think that in other places you just couldn’t do it unless someone was working full time on it”

CCG Cancer Clinical Lead

“Without the day to day leadership of the Project Manager it would have been much harder to deliver”

Consultant Chest Physician

Interpretation
The Project Manager was extremely experienced and as a result was able to establish herself quickly and “hit the ground running”. She supported the development and implementation of the service and is now ensuring that systems and processes become embedded. It was acknowledged by a number of interviewees that without the dedicated resource of a Project Manager it is doubtful whether so much progress would have been made due to lack of capacity and project management skills of other key stakeholders.
C.1.3.2 Funding for LHLP services (Mb)

Context and Mechanisms

Prior to implementation of the project there was significant commitment from the CCG, local acute providers and the local cancer community to do something to improve the lung health of the population. Liverpool Public Health also supported the activity related to phase 1 of the project but was less convinced about the proposals for the case finding approach that made up phase 2 of the project.

Liverpool CCG was committed to piloting the healthy lung project and spent a significant amount of time identifying all of the elements of the project and associated costs. A business case was approved and funding made available for the project. In addition, ACE funded the Project Manager for the first year and also provided some additional support in the form of some evaluation as part of the overarching ACE programme evaluation.

Characteristics of mechanisms and outcomes

“Liverpool CCG funded the Project Manager from year 2 onwards . . . . . . . We’re funding the phase 1 intervention in its entirety, so that’s staff to manage community events, to put those on. The resources, booklets, spirometry service to support those, as well as the room hire where that’s required, fruit and veg bags for participants and refreshments and stuff. So we’re funding the entirety of the community events, and there’s budgets, there’s a small budget in there for advertising. We are also funding a one year evaluation of those community events . . . . . . We then as a CCG funded GP (practice) engagement in the project. So we funded that. We pay for an initial meeting with the practice to explain the clinical pathways. We pay per patient for the practice to send out the first two letters . . . . . . We’ve paid Liverpool Heart and Chest Hospital for the admin staff to run the service, for the nurses, we’re paying the trusts for all the scans that are associated with this”.

Cancer Transforming Services Manager

“We are putting in all the GP (Macmillan GP) time and input.”

Cancer Transforming Services Manager

Because a robust evaluation of the project was required to secure the ongoing funding that would enable the project to be rolled out across the whole of Liverpool, funding for a local evaluation came from the CCG.

Other elements of the project were funded by Specialist Commissioning:

“Specialised commissioning, we spoke to them to say we think we’ll find more lung cancer, therefore that has an implication on your surgery rates, because specialised commissioning fund surgery and chemotherapy. So specialised commissioning has modelled some assumptions around the potential costs of treatment for the patients we may find. So that comes out of their budget.”

Cancer Transforming Services Manager
One area which was not included in the business case for funding was the cost of diagnostic spirometry. The number of patients requiring this is significant and will have a financial impact on Liverpool CCG. An additional cost, not considered in the business case, was the need for the CCG to pay for legal advice regarding the ability to share patient level data across organisations, although they did identify a contingency fund which supported this kind of activity.

**Interpretation**

Modelling the project and development of the business case allowed many of the costs associated with the project to be factored in and properly funded. These included both the services and professionals time. However, some costs were not anticipated in the original business case.

**C.1.3.3 Connections and communication between professionals and stakeholders and ownership at all levels and across all organisations (Mc)**

**Context and Mechanisms**

There was agreement across a wide range of stakeholders, both statutory and voluntary, that lung cancer and lung health in general was a real problem in Liverpool, and this was supported by the evidence base. There was also consensus that high mortality rates, late diagnosis of cancer, and fatalism associated with a lung cancer diagnosis meant that relying on existing models of care would not result in sufficient improvement and that something new needed to be tried. A business case was also developed to support a pilot for a Liverpool wide case finding programme aimed at targeting people at risk of developing lung cancer.

**Characteristics of mechanisms and outcomes**

A multidisciplinary multi-provider project team was established to reach consensus on the proposed approach and confirm the clinical pathway. This involved CCG cancer lead clinicians, providers from acute trusts (The Royal Liverpool and Broadgreen University Hospitals NHS Trust; Aintree University Hospital NHS Foundation Trust; Liverpool Heart and Chest Hospital NHS Foundation Trust) who were providing the existing pathway and Liverpool Public Health. An investment proposal was developed by Liverpool CCG together with a Project Initiation Document (PID).

Whilst there was consensus regarding the way forward from the majority of stakeholders, Liverpool Public Health expressed several concerns in relation to this proposed approach. Their concerns were primarily over the lack of robust evidence at that time related to screening for lung cancer. They also posed the question as to whether low – dose CT screening would add incremental benefits over tobacco control and would save enough additional lives to offset any potential harm it may cause. The challenge from Liverpool Public Health proved to be positive with a number of interviewees commenting on how it helped them really focus and refine what they were trying to do:
“Sometimes it’s uncomfortable when you don’t agree on the way forward but with hindsight their concerns were really valid and deciding to go ahead against their advice as it were meant we had to be extra cautious that we were doing things for the right reason and that we had a clear rationale for what we were trying to do”

Macmillan GP

“I now view Public Health as providing a critical friend function”

Project Manager

Throughout the interviews there were examples of ownership of the project at all levels and across all organisations:

“I think we’ve got a community of enthusiastic, really committed people who’ve really had to think clearly and carefully about the evidence and about what we are going to do and who has ownership of what. I think we’ve really raised the profile of lung cancer as an issue. I think we’ve brought together a partnership of people who actually all want to move in broadly the same direction to make a difference”

Cancer Transformational Change Manager

“The beauty of this project, and I’m a secondary care physician, is the passion you feel from everybody to make it work and that’s why I think, it’s incredibly complex, its involving a whole city, its transcending boundaries that don’t often get transcended, yet there is still positivity from every angle”

Consultant Chest Physician

A significant amount of work was also required to ensure data sharing across organisations because organisations all had different guidelines regarding patient level data and legal advice was required to ensure that the CCG was Caldicott compliant:

“I hadn’t really anticipated information sharing across partners being so complex, where you’re actually trying to share data for evaluation across partners. As a CCG we shouldn’t really have patient identifiable data but we have consent to hold that data, which is why we can. So first of all our ability to hold and use data as any other service provider is challenged; however, none of our providers have contracts with EMIS, and therefore couldn’t really take on that role. So data ownership we had to establish that, then the ability to data share.”

Cancer Transforming Services Manager

A communication plan was also developed to ensure that robust communication pathways were established for the duration of the project.

Interpretation

Good communication has been essential in terms of ensuring that all of the different stakeholders continue to feel they have a key role in this very complex project. The Project Manager role has been vital in ensuring that people are communicated with in a timely and appropriate manner using a range of materials, without this level of input there is a risk that people do not understand their role and how it fits with the wider process, there is also a risk of people becoming disengaged if they feel that
they don’t know what is going on. The data sharing issues have been complex to resolve due to lack of national information governance agreements in place.

C.1.3.4 Steering Group (Md)

Context and mechanisms

A steering group was established including key stakeholders including the representatives from the CCG, Public Health, local acute providers and community representatives prior to the project commencing. The steering group also ensure that there was representation at the ACE cluster group meetings.

Characteristics of mechanisms and outcomes

A monthly Steering Group was established to shape the delivery of the project. The steering group was chaired by the Liverpool CCG Chair, supported by the Project Manager. Membership included Macmillan GPs, Consultant Clinicians, Radiology, Public Health and the Cancer Transformational Change Manager and 3 lay members, all of whom who have extensive experience in volunteering in cancer services and two of whom who have experienced lung cancer.

7 work streams were identified:

- Governance
- Outcomes and evaluation
- Information management and technical
- Information governance
- Finance, contracts and procurement
- Engagement and communications
- Service delivery (including clinical pathways)

Each work stream had a named lead appointed by the steering group. Initially the work streams reported on a monthly basis to the steering group, though this reduced for some as the work streams addressed their objectives.

The work streams were effective in ensuring the large amount of work required to achieve implementation of this project occurred. They also identified problems at an early stage and to some extent identified potential problems and solutions prior to them being taken to the steering group for final resolution:

“The way we’ve managed the project with the work streams has gone well, we lead work streams where we have the most expertise so we really do understand the issues faced by our work stream, they are task related groups so they aren’t about nice fluffy discussions, they are about getting the work done. We then feed into the Steering Group which has been a very effective way of managing things”

Macmillan GP
Interpretation

One of the reasons for the success of the Steering group was that the membership had a shared vision; individuals were responsible for leading work streams in which they had expertise and which for the most part would impact directly on their roles. The Steering group was also effective because there was strong leadership and clear lines of accountability and members of the group were senior enough to be able to take and implement operational decisions.

C.1.3.5 Insight work (Me)

Context and mechanisms

As part of the work to review the evidence base particularly for phase 1 of the project Liverpool CCG and Liverpool Public Health were keen to understand how best to engage with their local population groups. Prior to implementation of the project some insight work was conducted to try to ascertain how best to engage with some of their previously identified population groups:

“We’ve done a couple of stages of insight work where basically we’ve explored with unconfident fatalists and live for todays, two of our population groupings and healthy foundation segmentation that we are interested in. And basically we explore with them attitudes towards lung cancer and COPD”

Cancer Transformational Change Manager

Characteristics of mechanisms and outcomes

The insight work proved to be influential in helping shape the project, particularly in relation to phase one (community events):

“We found that lung cancer was the most feared cancer, they view getting a diagnosis is worse than the treatment, you’re better off not knowing, people not wanting to talk about it. People feeling there’s nothing you can do and it’s an automatic death sentence. So we understand that there’s huge fear and fatalism. We then engage people around how best to start these conversations. We know leading with cancer doesn’t work; people don’t want to talk about cancer. Talking about smoking also does not attract people in that risk group . . . . . . But we tested out the concept of a healthy lung and people thought it was a new health topic. They were quite interested in that and they saw that it was quite helpful, interesting and were keen to explore it”

Cancer Transformational Lead Manager

Interpretation

The insight work heavily shaped the way the community events were delivered and how conversations about lung health were structured. Without this work a more traditional approach focusing on lung cancer risk and smoking cessation might have been employed.
C.1.3.6 Service and pathway design (Mf)

Context and mechanisms

A 2 phase model was developed (see C1.1.2). Prior to implementation of the project insight work was conducted that shaped the discussions about lung health that were subsequently employed in the community events which constituted Phase 1 of the project. Phase 2 involved practices inviting a clinically targeted population group as previously described to engage with the practice for a lung health check. It was anticipated that a proportion of Phase 1 attendees would go on to participate in Phase 2.

Characteristics of mechanisms and outcomes

Phase 1 – Community events

Phase 1 was supported by Liverpool Public Health and the Community Health Ambassador team who were commissioned by the CCG to deliver Phase 1 of the project in the selected communities. This work was rolled out on a neighbourhood by neighbourhood basis, starting in the area with the highest incidence and mortality. Events were set up either as standalone or were added on to existing events.

Local practices were asked to endorse and support events. Bags of free vegetables were used to entice people in to the events. Once there, they had opportunities to talk to health professionals about lung health, take part in interactive activities and have a (non-diagnostic) spirometry test.

At the time of the final interviews the events planned for one area had been completed with those for a second neighbourhood in progress. At that point approximately 1,200 people had attended events. Feedback from the events was very positive. However, some interviewees commented that there did not appear to be a correlation between those attending the community events and those who subsequently went on to accept an invitation to a lung health check. Some suggestions were offered as to why this might be the case:

“People coming to the clinic are asked whether they’d been to a community event, the vast majority to date said no, but when you go to an event and look around that’s not so surprising because the age profile is younger than that which we are targeting. So I think the jury’s out on how well the community events work to influence uptake of invites”

Macmillan GP

“People seem to like the community events, I’ve never been to one but anecdotally they are liked but I think we’ll have to revisit their value and whether we’ve got the target audience right because hardly any of those who’ve been for a lung health check say they were at a community event first. So maybe we need a bit of a rethink”

Consultant Chest Physician

“So quite a lot of the patients attending are not in our target group. I think the impact’s terribly difficult to measure because it (the community events) does raise the profile in the community so even if the people aren’t actually in your target
As well as staffing the community events with the Community Health Ambassador team, it was originally hoped to develop some community champions to help support this work. This has been less successful with only a few community champions being recruited. However, the Healthy Lung Public Engagement Group have provided support which to the community events which has been viewed as valuable.

Phase 2 - Invitation to a lung health check appointment

Phase 2 involved practices sending out invitations to patients who fulfilled the criteria (as previously described in the ACE model section of this paper). The Project Manager, Macmillan GPs and Lung Nurses all spent a significant amount of time working with practices to educate them about the project as a whole but also about the specific processes and their role within the pathway. Practices were asked to send out invitations to selected patients 2 weeks prior to the nurses running the clinics in that area. A process to send out reminder letters and follow up non-responders by telephone was also developed. On receipt of an invitation patients were requested to telephone a designated number to book into a clinic.

In order to deliver the lung health check appointments three WTE equivalent nurses were appointed.

Initially, the response rate to the invitations was so great, because everyone responded at the same time, that additional admin capacity had to be found. It appeared that the majority of patients who were interested in accepting the offer of an appointment did so very quickly after receipt of the invitation thus causing a bottleneck on the booking line.

With hindsight interviewees thought that the initial target of 70% uptake was ambitious. At the time of interviews the response rate was 43%. It has been speculated that insufficient capacity to answer appointment phone lines when the invitations were sent out may have deterred some patients. However, uptake in the second locality was higher:

“I think we picked the hardest area to start with and we had some significant challenges and we had some considerable teething problems over the invites . . . . . admin were getting very overwhelmed with phone calls. People were having trouble getting through to make appointments . . . . . we have different challenges as we move into the next area but I’m hopeful that uptake will improve.”

Macmillan GP

“It’s early days in this 2nd area and there are still challenges but I think uptake is increasing but we’ll have to keep a close eye on it”

Lung Nurse
When patients attended for an appointment they were seen by an experienced nurse who was employed by Liverpool Heart and Chest Hospital and primarily worked within community settings and occasionally in GP premises. Within a 45 minute appointment patients were assessed by this nurse and a “My Lung Risk Score” generated. Those patients with a 5% or great risk were then offered a referral for low dose CT Chest scan. Patients accepting the CT scan offer were referred to the radiology unit at the local hospital and the patient was subsequently contacted by that unit to arrange the appointment.

Initially 30 minutes were allocated for a lung health check, based on a trial run through of the appointment process before the nurses came into post:

“They found that it (the clinic consultation) was taking quite a long time so we extended the consultation time from half an hour to 45 minutes. And we sort of tried to bring it back down again but the nurses were saying we really need that 45 minutes.”

CCG Chair

The main reasons cited for needing longer were 1) significant numbers of patients presenting in the first area whose first language was not English and the logistical problems resulting from that e.g. needing to arrange interpretation services, and 2) the length of time needed to get consent for patients’ data to be used for evaluation and research purposes.

Of those people attending for a lung health check appointment, 35% were eligible for a scan; this was higher than had been anticipated from the modelling conducted prior to starting the project.

Among those offered a scan uptake was high:

“So of those being offered scans I think it’s about 95% on average are accepting the offer, which is much higher than we thought”

Project Manager

One unintended consequence of the lung health check related to patients whose risk was lower than 5% and who did not therefore fulfil the criteria for CT scan:

“What we didn’t expect as well, we thought people who would be offered the scans would be actually afraid to take up the offer, and actually so far it’s completely the opposite. People who were told – great news, you don’t meet the threshold to be offered the scan are actually really disappointed and quite annoyed. . . . . . . We’ve actually had to develop a short flier to support the nurses in saying look I’m not referring you for a scan and this is the reason why”

Project Manager

Nevertheless, interviewees felt that the consultations worked well and feedback from patients had been good. In addition, comments from the external evaluator were also positive:

“The consultation works well. We’ve had a couple of people come and sit and observe the nurses including our external evaluators and they’ve said how well organised it feels and how personable the nurses are, and how great their consultation skills are. So that’s going well”
Project Manager

One area which proved problematic and difficult to resolve were issues with IT systems being incompatible and IT equipment not working in community venues. This resulted in the CCG Project Manager getting more involved with practical issues in order to resolve problems where they arose, notably in some of the less well equipped community venues.

On one hospital site the Radiologists were struggling to report the scans within the agreed time (the target was 90% of scans results to be reported and feedback to the project lung nurses within 5 working days, the remainder to be reported in within 2 weeks of the scan date). The nurses were managing the process by identifying patients who had exceeded the 5 working day target and liaising with Radiology to ensure that they were scanned and reported on within 2 weeks. At one stage 136 people were waiting to have their scans reported. This was being managed and monitored on a daily basis, and a neighbouring trust (also part of the project) were providing additional reporting capacity.

Of those patients who had scans reported, we were informed that the proportion of screened patients with pulmonary nodules was lower, at 10%, than the anticipated 25%. It was also reported that a small number of lung cancers had been found, as had some other clinically relevant findings which had been fed back to patients’ GPs:

“And so far so good, we are finding lung cancer. The lung cancer we are finding is resectable and curable. The worry about us finding lots and lots of nodules that would put the patient through hell for nothing, we’re finding significantly less nodules on the first tranche of data than we might have expected to find. And I think of the alert images for unexpected findings, all of them are relevant and have been feedback to the GP to action, so the pneumonias and the fibrosis and the aneurysms and things”

Consultant Chest Physician

Interpretation

Without exception everyone interviewed felt that the pathway was a good thing for patients and that most of the processes worked well, with the pathway becoming established and starting to become embedded. However, there was acknowledgement that there had been significant challenges in implementing the pathway, both operational and strategic and that proactive and timely management had been a key factor in ensuring effective resolution of these.

C.1.4 Conclusions

Some of the outcomes specified in the CMO table (figure 5) were successfully achieved and will be sustainable; for others success and sustainability is less clear:

O1.Changing attitudes about cancer – both phase 1 and phase 2 were designed to change attitudes about lung cancer, however at this stage of the project we have no
evidence to support that this has been the case. Some work is planned with attendees at the community events to explore this via exit interviews.

O2. Evaluation of project – an external evaluation has been commissioned and is due to report after April 2017. Everyone who was interviewed reported that the pathway was a good thing for patients.

O3. Earlier presentation of cancer – anecdotal evidence from the interviews suggests that cancer is being detected at an early stage. Early data collection also supports this.

O4. Change in health inequalities – it is too early to determine whether this project will change health inequalities in Liverpool.

O5. Identification of people at high risk – the project appears to be effective from a case-finding perspective as it has identified people with a >5% risk of developing lung cancer and has also identified a small number of early lung cancers in those who have been scanned to date.

O6. Identification of COPD cases – there is anecdotal evidence to suggest that the project has been effective in identifying previously undiagnosed COPD; this is also supported by initial internal data collection.

O7. Consistent services and pathway implementation across sites and region – it is too early to say whether there has been consistency in pathway implementation at this stage of the project. There still needs to be work done to ensure that service provision is consistent across sites.

Applying a Normalisation Process Theory framework to our findings, we conclude that the service has been normalised to some extent. At present there are some problems with capacity for Radiology reporting on one site, however the close monitoring of the project means that operational problems can be addressed in a timely manner and so help embed and normalise the service. A summary of the factors associated with the normalisation of the project is shown in table 6.

Table 6  Factors associated with normalisation of the Liverpool Health Lung project

<table>
<thead>
<tr>
<th>Coherence</th>
<th>Cognitive participation.</th>
<th>Collective action</th>
<th>Reflexive monitoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the work?</td>
<td>How does the work get done?</td>
<td>How is the work understood?</td>
<td></td>
</tr>
<tr>
<td><strong>Systematic explanation of mechanisms and components at work</strong></td>
<td>The CCG, Acute providers and GP practices recognised it as building upon previous work. Education events and regular feedback from the Macmillan GPs, Project Manager and Lung Nurses have reinforced the mechanisms of the process.</td>
<td>Practices send out the invitations. Lung Nurses do the assessment, and refer to radiology for low dose CT if risk &gt;5%. Scans done within secondary care. GPs informed of results. Where findings require it patient moved to appropriate pathway.</td>
<td>Training was provided in relation to the pathway and what was expected of practices. Nurses were given in-depth induction and ongoing support for nurses was provided by the Macmillan GPs, Project Manager and Chest Consultant.</td>
</tr>
<tr>
<td><strong>Working closely with the steering group held appraisal of systems and processes by all stakeholders involved</strong></td>
<td></td>
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</tbody>
</table>
| Knowledge about the sources and operation of investments at work | Not all practices understood the mechanism of inviting patients and how it linked with the healthy lung project.  
The Steering group understand Radiology reporting capacity issues | Value of the intervention was promoted by proponents of the service from across Liverpool  
There was consensus that the intervention was worthwhile from a patient perspective and this was evidenced via the insight work | GP practices engaged in inviting patients to a healthy lung check appointment  
There is good understanding of factors affecting the pathway across key stakeholders with the with the Steering group proactively managing issues and continuing to shape and develop the service as it rolls out and as they get an opportunity to scrutinise data |  |
|---|---|---|---|---|
| Core questions | How is a practice conceptualised by participants?  
Viewed positively by General Practice, Secondary care and those delivering the service | How do participants come to engage with a practice?  
Practices were initially approached by the Macmillan GP's. The project was actively supported by the CCG. More sustained engagement due to education and training of practices and ongoing support provided to practices by the Project Manager | How do participants enact a practice?  
Follow protocol. Enlist support from Project Manager when necessary. | How do participants appraise a practice?  
Appraisal and feedback encouraged via the steering group and regular contact with the Project Manager |  |
| How does it hold together in action?  
Most GP Practices sending out invitations as and when required, although this process is under review due to a practice forgetting. Radiology coping with demand for the CT scans, one site has problems with reporting capacity and is being currently supported by another site. All stakeholders feel that the service is worthwhile although questions of cost-effectiveness remains | How do they decide on engagement and the purposes that it serves?  
Discussions around value to the patient, value to the whole health economy. Consideration of additional workload and subsequent impact on capacity.  
Project driven by the CCG supported by a multidisciplinary, multiagency Steering Group | How are their activities structured and constrained?  
Practices are responsible for inviting the patients to a healthy lung check. Nurses are responsible for assessing the patients risk and if appropriate referring them to radiology. Radiology are responsible for CT scan and reporting. GPs responsible for those without significant disease, patients with alert images to be dealt with on appropriate pathway. | What are its effects of appraisal?  
Appraisal has resulted in changes to the way practices send out invitations. Appraisal has also led to the development of an information leaflet explaining why some patients do not meet the criteria for a CT scan. Regular appraisal of the data also raises questions to be discussed at the Steering Group |
Appendix D Vague Symptoms Cluster Case Studies

The Vague symptoms cluster comprises ten projects focusing on the pathway for patients presenting with symptoms that may not be covered by existing pathways or where the primary cancer site is unclear. The projects include audits of cases where early symptoms were vague, pathways for symptoms such as weight loss or jaundice, electronic referral and triage and multi-disciplinary diagnostic centres. They include primary care, secondary care, academic and commissioning settings.

While the projects focus on different areas and settings, they all aim to improve the outcomes and experience for patients in whom cancer is suspected, but the primary site is unknown or unclear.

Three projects within this cluster were chosen for the qualitative evaluation:

- Airedale, Wharfedale and Craven CCG
- Chesterfield CCG
- London Cancer (University College London Hospitals NHS Foundation Trust and Barking, Havering and Redbridge University Hospitals NHS Trust)

These projects aim to improve patients’ access to care, streamline current provision and provide GPs with support to refer for appropriate diagnostic tests or clinics.

Airedale, Wharfedale and Craven CCG established an electronic referral system for GP to receive triage advice from radiology. Chesterfield CCG developed a multidisciplinary cancer of unknown primary (CUP) clinic. London Cancer piloted a multidisciplinary diagnostic clinic (MDC) for patients with abdominal symptoms at two different hospital sites.
D.1 Airedale, Wharfedale and Craven Clinical Commissioning Group and Airedale NHS Foundation Trust electronic referral advice pathway

The following case study describes the implementation of an electronic referral advice pathway. The project is ongoing and this qualitative evaluation covers the period to June 2016.

D.1.1 Introduction and Background

Airedale, Wharfedale and Craven Clinical Commissioning Group is made up of 17 GP practices, supporting a population of approximately 156,000 people in a large geographical area stretching from Oakworth and Keighley in the south to Settle in the north. The population is growing at a rate of 1% annually and Airedale, Wharfedale and Craven also has an ageing population with 9.2% of the population being aged 75+ versus a national average of 7.5%.

Cancer is the leading cause of premature death and the second most frequent cause of all deaths in the area. Airedale, Wharfedale and Craven Clinical Commissioning Group have a higher incidence of cancer than the national average and also higher than average 2 week wait (2WW) referral activity. In addition, Cancer GP profiles show that there is large variation in activity amongst individual practices.

Following the local establishment of a Malignancy of Unknown Origin Fast Track service it was apparent from discussions with primary care that there was a need to improve the support GPs received from the Radiology Department in order for them to target their direct access investigations more effectively.

Urgent communication between Radiology and Primary care had proved challenging given the clinical commitments of both specialties, however, there was a view that better communication with Radiology would lead to more appropriate imaging requests in patients with suspected malignancy of unknown origin.

Airedale, Wharfedale and Craven Clinical Commissioning Group and Airedale NHS Foundation Trust already operated electronic referral services to certain specialties and they were keen to expand this development. Radiology was part of this expansion, as was Respiratory Medicine, which also had plans to improve communication around the most specific investigations for patients at high risk of lung cancer.

The ACE project encompassed the whole of the Airedale, Wharfedale and Craven area.

D.1.1.1 Aims and Objectives

The overall aim of the project was to enable GPs to send electronic requests for referral advice requests to Radiology and for this to be an urgent service so that the correct imaging could then be organized within a two week timescale.

Specific objectives included:
• Establish a new electronic referral system from GPs to Radiology in order to receive advice on the most suitable imaging for a patient with suspected cancer presenting with vague symptoms, and for a referral to be seen within 2 weeks.

• To provide support, education and training to GP practices in the early detection of cancer.

• To develop an electronic referral pathway form.

• Each GP practice to conduct an audit on their cancer referrals. This would provide an understanding of activity within the health economy and feed in to a clinical cancer dashboard. This will also provide a toolkit for GP educational requirements and enable identification of high risk patients.

• Develop an educational package, including identification of early cancers, signs and symptoms, communication and breaking bad news. A training programme will be delivered to practices in accordance with the identified needs.

D.1.1.2 ACE Model

The new pathway was developed in accordance with NICE guidance on the investigation of Metastatic Malignancy of Unknown Origin.

GPs were required to provide clinical details and relevant past medical history as well as an indication of the test they thought would be most appropriate. The referral was sent electronically and seen by a Radiologist who then provided advice about the most appropriate imaging. The timescale for advice was to be two working days. The referral for test would then be made and conducted within two weeks.

The format for the referral form was to be structured in a way that made the information requested as relevant as possible and allowed the steering group to evaluate how many requests were altered in light of radiology advice.

Following the development and operationalization of the referral pathway there were plans to develop an educational package for primary care clinicians to allow them to understand how to engage with the process and how to identify the most relevant patients. There were also plans to organise a locality-wide education event and invite the Radiologists to explain how to maximize the use of imaging for suspected cancer patients. In addition, the GP Cancer Lead intended to visit individual GP practices to demonstrate the system and encourage reflection on late cancer diagnoses and to consider how the use of imaging in primary care may have facilitated a more speedy diagnosis.

Audit data on late diagnosis and learning points from case reviews were to form the basis of case discussions, in addition, the last ten cases of lung cancer in one practice of 13,000 patients would be reviewed to assess whether there was an opportunity for earlier intervention with imaging. The audit templates would be shared with the
practices in order for them to evaluate their current practice and to encourage engagement with the new referral process.

The steering group would monitor the uptake of electronic referrals and assess what impact the triage service had on the following:

- Total volume of imaging requests
- The % of requests being altered by the triage process
- The conversion to cancer rate for the requests
- The impact on stage at diagnosis of lung cancer within Airedale General Hospital
- The impact on stage at diagnosis of other types of cancer within Airedale General Hospital
- The rate of admissions with new cancer diagnosis
- The rate of referrals to the Malignancy of Unknown Origin (MUO) clinic

D.1.1.3 Project Scope

The pathway was to be piloted initially for six months with a view to rolling it out to a year if early data looked promising. ACE provided funding for the 12 month period.

D.1.1.4 Implementation

The project was led by the GP Cancer Lead, supported by the steering group. The project commenced on the 1st June 2015.

D.1.2 Methodology

The qualitative evaluation of the ACE programme draws on the principles of realist evaluation (Pawson and Tilley, 1997) to develop a contextualised account of the way in which change emerges. See section 2.1 for details of realist methodology. For the purposes of this case study, a total of 12 1:1 interviews with key informants were carried out.

Analysis of the interviews resulted in the development of a Context, Mechanisms and Outcomes (CMO) model (figure 6)

The CMO model considers the contexts, mechanisms and outcomes that were apparent in the implementation of the initiative. Each of the key mechanisms is considered in turn within the case study.

Normalisation Process Theory (NPT) provides the theoretical basis for understanding how the initiative is understood, implemented and embedded into normal practice. NPT considers four areas; coherence, cognitive participation, collective action, and
reflexive monitoring. See section 2.2 for details. Each of these areas are considered in turn in table 7.

<table>
<thead>
<tr>
<th>CONTEXT</th>
<th>MECHANISM</th>
<th>OUTCOME</th>
</tr>
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<tbody>
<tr>
<td>C1. ACE programme</td>
<td>Ma. Electronic referral to radiology service design and implementation</td>
<td>M1. Awareness raising and education for professionals</td>
</tr>
<tr>
<td>C2. Small geographical area with coterminous CG and secondary care</td>
<td>Mb. Steering group</td>
<td>M2. Pathway evaluation</td>
</tr>
<tr>
<td>C4. Restructuring and loss of previous organisations and networks</td>
<td>Md. Connections and communication between professionals</td>
<td>M4. Reporting/administration processes</td>
</tr>
<tr>
<td>C5. 6 month pilot</td>
<td>Me. Leadership</td>
<td>M5. Audit</td>
</tr>
<tr>
<td></td>
<td>Mg. Data collection and sharing</td>
<td>M7. Data collection and sharing</td>
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<td></td>
<td>M8. IT in place</td>
<td>M8. IT in place</td>
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<td></td>
<td></td>
<td>O1. Faster route to diagnosis</td>
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<td>O2. Understanding of staffing/capacity needs</td>
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<td>O3. Detection of diseases other than cancer</td>
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<td>O4. Conversion rate</td>
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<td>O5. Streamline pathway and develop protocols</td>
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<td>O6. Engagement from all relevant departments</td>
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<td>O7. Reduction in number of tests and appointments</td>
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<td>O8. Uptake of pathway</td>
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<td></td>
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<td>O9. Roll out to other areas and sustainability</td>
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</tbody>
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Figure 6 CMO model for Airedale, Wharfedale and Craven Clinical Commissioning Group and Airedale NHS Foundation Trust electronic referral advice pathway

N.B. We do not specifically discuss the second cluster M1-M9 because they are components of the mechanisms discussed Ma-Me

Each mechanism Ma-Me will be discussed in the following section:

D.1.3 Contexts, Mechanisms and Outcomes (CMOs)

D.1.3.1 Electronic referral to radiology service design and implementation (Ma)

**Context and Mechanisms**

GPs and the Trust have previous experience of electronic referrals services to some specialities. The referral criteria and electronic referral form for this pilot were developed by the steering group; the process was initially piloted for six months and then rolled out for a further six months.

Support was sought and promised from the Commissioning Support Unit during the planning stages of the project, however due to capacity issues and changes in organisational structure, their input proved to be minimal.
Characteristics of mechanisms and outcomes

In order to support the implementation of the referral pathway, formal education events were provided in addition to the GP Cancer Lead visiting every single practice to encourage use of the pathway and feedback inappropriate usage. The GP Cancer Lead also used the practice visit as a means of getting feedback re the pathway:

“I’ve had one GP who said it was excellent because he’d got really good advice from Radiology.”

GP Cancer Lead

As a result of the GP practice visits, the GP Cancer Lead became aware of practices who were not confident in using the technology in order to make an electronic referral. As a result they did not have the technical skills to upload and access the referral templates on their practice systems. In these instances the GP Cancer Lead provided support from her own practice staff to ensure they were confident and competent in using the technology. This approach was successful as it ensured that all practices engaged with the process and it was felt that the numbers of inappropriate referrals decreased. In total 62 GPs from the 17 practices made referrals to this service.

The Radiologists were able to respond in the specified timescale and patients were booked in for the recommended test within two weeks as planned. They also perceived it to be a valuable service:

“Yes it’s been a real success; patients get the appropriate test first time round so there’s no wasting of time . . . . and from an patient and education perspective GPs get to know quickly as to what’s the best next investigation for somebody. They may not know what’s the next step, in terms of CT, MR or something else, so I think the process has really helped them”

Consultant Radiologist

As well as being viewed as successful from a GP and Radiology perspective, it has also been viewed as a success from a commissioning perspective.

The Quality Support Manager developed a GP survey on SurveyMonkey asking the following questions:

- How useful was the e referral advice service in helping investigate your patient?
- Did you find the service response time satisfactory?
- Did the advice change your initial thoughts on which investigation was most suitable?
- Based on your experience, would you be likely to use this service in the future?
- Would you recommend this service to others?
- Would you like to give any further feedback on this service?
Unfortunately only nine GPs responded, all of whom would have recommended this service to others.

**Interpretation**

The input from the GP Cancer Lead into every practice was a key factor in getting widespread engagement. It should be noted that although the area is large geographically, the number of GP practices is small. Visiting every practice to secure engagement would be less feasible in an area with many more practices, without more GP Cancer Lead capacity.

The poor response to the survey by GPs is not uncommon and probably reflects competing priorities and clinical pressures.

**D.1.3.2 Steering group (Mb)**

**Context and Mechanisms**

The steering group operated within the context of the ACE programme it is relevant that the area is geographically well defined with a coterminous CCG and secondary care trust.

A steering group that included key stakeholders was established prior to the project commencing.

Initial input from the radiology department was unhelpful as the first clinicians to become involved were unhappy about the electronic processes involved and wanted to establish it as a paper based service. This was resolved when the Lead Cancer Manager intervened and sought input from other radiologists.

**Characteristics of mechanisms and outcomes**

The project was led by the GP Cancer Lead, supported by the Quality Support Manager from the CCG.

Monthly Steering Group meetings were held to shape the delivery of the project. Membership included the GP Cancer Lead, Lead Cancer Manager, Consultant Radiologists and Consultant Respiratory Physicians

“The steering group was formed and made up of key individuals who could influence and implement the processes. It worked well but a lot of work was done outside that forum with members of the group getting on with it and then feeding back.”

Lead Cancer Manager

The Steering Group was effective in getting the project implemented and dealing with operational issues, once the members had agreed the purpose and scope of the project. The steering group went on to successfully bid for ACE Wave 2 funding, which builds upon the learning from this project.

The Cancer Lead Manager retired midway through the project and this could have been a risk to the project. However this did not materialize because the project was
high on the Trusts agenda and a thorough handover was made possible, including a period of shadowing for the incoming manager.

**Interpretation**

One of the reasons for the success of the Steering group was that the membership had a shared vision, was close enough to the work for it to impact on their roles and were senior enough to be able to take and implement operational decisions. There was also strong leadership and clear lines of accountability,

**D.1.3.3 Evaluation of staffing capacity (Mc)**

**Context and Mechanisms**

This project was undertaken in the context of organisational restructuring and the loss of previous networks.

Some initial work to assist project planning and capacity modelling was undertaken by the Commissioning Support Unit. However, due to capacity issues and changes in staffing this was not as detailed as the project lead had anticipated:

“The biggest challenge was getting information out of the Commissioning Support Unit, they said they would support us and then couldn’t deliver due to capacity issues of their own, that was really frustrating”

GP Cancer Lead

Initially it was appeared that there were capacity issues in Radiology but following a change in the radiology individuals involved in the project, the capacity problem was resolved:

“Actual capacity in Radiology was difficult; I think they had a lot of untoward workforce issues that coincided with our bid being accepted. But having said that I think they really got their team galvanized, and I’m really impressed with how much they’ve come on board despite those capacity issues”

GP Cancer Lead

**Characteristics of mechanisms and outcomes**

As previously discussed the e-referrals were made to a Radiology inbox specifically for suspected cancer vague symptoms. This inbox was serviced by two Consultant Radiologists who checked it at regular intervals. The Trust was paid the tariff rate of an e-consult for these referrals.

The volume of referrals did not present a problem and there was sufficient Radiology capacity to respond in the specified timescales. However there was recognition that had the numbers increased substantially then capacity may have become an issue:

“If the numbers increase as we move forward then that might become an issue but at the moment numbers are small and manageable”

Consultant Radiologist
Initial work with the CSU looked at potential capacity so the service was modelled on that basis. They also reported that as a relatively small District General Hospital unexplained spikes in demand were uncommon.

**Interpretation**

Careful monitoring and discussion in the Steering Group appears to have facilitated a robust understanding of capacity issues.

**D.1.3.4 Connections and communication between professionals (Md)**

**Context and Mechanisms**

Two mechanisms, the Steering Group and the practice visits by the GP Cancer Lead, were key to enable communication between the professionals involved in the planning, implementation and delivery of the pathway (see Mb for more detail).

**Characteristics of mechanisms and outcomes**

As previously stated, the steering group was effective due to its shared vision and consistent messages to primary care. The GP visits were critical in reminding GPs of the existence of the service and in giving them specific advice on how and when to use it. Wider education intended to raise awareness of the importance of early diagnosis also took place during the GP Practice visits.

The GP bulletin, which went out every Friday to the GPs from the CCG, provided regular and consistent communications about the project and was a useful opportunity to reinforce messages.

**Interpretation**

The importance of the need for providing consistent messages in a range of format is vital if all stakeholders are to be reached.

**D.1.3.5 Leadership (Me)**

**Context and Mechanisms**

The overall leadership for this project came from the GP Cancer Lead supported primarily by the Lead Cancer Manager from the hospital and the Quality Support Manager from the CCG and then the wider steering group. The well-defined geographical area with coterminous CCG and secondary care was a key context in this mechanism.

**Characteristics of mechanisms and outcomes**

The GP Cancer Lead did not use a project management model to assist in the implementation of the project; rather the approach was organic and pragmatic. It
did however rely quite heavily on good relationships with CCG board members and the goodwill of people wanting to work together:

“It helps that we’ve got really good relationships with the (CCG) board members, so it was easy to just pick up the phone and say please talk about this now because we’re about to launch and we can’t have this halting the final hurdle really. So I think the way it was able to be implemented so quickly was just because we’ve all got quite a good working relationship with each other”

GP Cancer Lead

Interpretation

This approach to leadership worked well with the project being delivered as planned with no major problems along the way. However it was heavily dependent on existing relationships and good will, which are possibly easier to cultivate in areas where the hospital and CCG are co-terminus and organisational structures are less complex.

Please see section 4.4 for further discussion about leadership and leadership theory.

D.1.4 Conclusions

One clinically important consequence of this work was how a timely diagnosis of even late stage cancer can be beneficial because it helps in terms of planning for preferred place of death and allowing time to consider other end of life issues:

“She was in a nursing home. She was really fit, her capacity was there, she’d just moved into the home and was trying to get back home . . . . she developed really severe upper abdominal pain . . . .when I saw her and she was telling me how much weight she’d lost and she’d got this non-specific abdominal pain that was going into her chest, and I was thinking you probably need a scan of your chest, abdo and pelvis. Whereas previously if I’d put that in, it probably would have been bounced back as too much imaging, or it would have taken forever. So I did an e-consult , within 5 days I’d had my e-consult reply, she’d had her scan and unfortunately she’s got what we think is an oesophageal malignancy with mets in her abdomen. Now she’s made decisions that she’s too frail and doesn’t want treatment, we’ve been able to give her pain relief and her family now knows. She’s now thinking that actually staying in the nursing home is the right thing. And she’s starting to feel more at peace with herself because she knows what’s wrong with her”

GP Cancer Lead

One aspiration was for GPs to conduct individual practice audits. The lead GP reported that a number of practices seemed ‘enthused’, but at the time of writing this report, no feedback regarding the audits had been received so the lead GP was unsure as to whether any had been started. A further aspiration was the development of a clinical dashboard. However, the strategic clinical network was charged with leading on this and no progress reports on this have been received to date.
To summarise, the outcomes specified in the CMO table (figure 6) were evidenced in the following ways:

O1. Faster route to diagnosis – there is a perception that often these patients were being sent for wrong diagnostic tests initially, leading to delays in diagnosis or managed in primary care for an unnecessary amount of time. Feedback from GPs to the project lead indicates that they do feel this is a faster route to diagnosis for cancer and non-cancer patients. During the interviews it was reported that 50% of patients have no disease found on imaging, however at the time of writing this paper we had not seen any data to support this.

O2. Understanding of staffing/capacity needs – the Radiology department understand their staffing needs to be able to deliver the service at current levels of demand

O3. Detection of diseases other than cancer – a review of all cases referred into the service has been undertaken and all of the non-cancer diagnoses have been recorded, these included a range of diseases including chronic liver disease and chronic pancreatitis. The project will be reporting more specific data to the CCG Board in the near future.

O4. Conversion rate – Interviewees report that the initial conversion rate was 21%, which reduced to 14% at the midpoint of the project and by the end of the project it was at 9.3%.

O5. Streamline pathway and develop protocols - the pathway has been refined as part of the development process and protocols have been developed

O6. Engagement from all relevant departments – there is evidence from the interviews of good engagement with relevant departments and across organisational boundaries

O7. Reduction in number of tests and appointments – there is a perception from steering group members interviewed that the number of inappropriate tests has been reduced, though we have not seen the data to support this, nor have we seen any data supporting a reduction in the number of appointments.

O8. Uptake of pathway – all GP Practices in the area have referred patients to this service.

O9. Roll out to other areas - this model has been promoted internally and shared externally with neighbouring areas and at the ACE Vague Symptoms Cluster Group meetings. In addition the learning from this project and the relationships established because of it were instrumental in the area securing funding from ACE for a Wave 2 bid.

Applying a Normalisation Process Theory framework to our findings, we conclude that many aspects of this project have been normalised (see section 2.2 for detail on Normalisation Process Theory), these have been analysed using an NPT framework and the results are shown in table 7:
Table 7 - Factors associated with the normalisation of E – Consult Pathway in Airedale, Wharfedale and Craven CCG

<table>
<thead>
<tr>
<th>Coherence</th>
<th>Cognitive participation.</th>
<th>Collective action</th>
<th>Reflexive monitoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systematic explanation of mechanisms and components at work</td>
<td>The CCG and GP practices recognised it as building upon previous work. Education events and regular feedback from the GP Lead have reinforced the mechanisms of the process</td>
<td>GPs do the assessment, and refer to radiology for diagnostic advice and imaging</td>
<td>Working closely with the GP Lead and CCG Manager has helped with appraisal of systems and processes by GPs and Radiologists</td>
</tr>
<tr>
<td>Knowledge about the sources and operation of investments at work</td>
<td>GPs understood the mechanisms of referral and how it linked with the e-consult service. Radiology understand capacity and demand issues.</td>
<td>Value of the intervention was promoted by proponents of the service, by appeals to ‘do the right thing’ and promotion of potential financial incentive to the hospital There was consensus that the intervention was worthwhile from a patient perspective</td>
<td>There is good understanding of factors affecting the pathway across key stakeholders with the CCG supporting the continuance of the service post project.</td>
</tr>
<tr>
<td>Core questions</td>
<td>How is a practice conceptualised by participants? Viewed positively though by those referring in and those delivering the service</td>
<td>How do participants come to engage with a practice? The idea that the pathway was better for patients encouraged initial engagement. More sustained engagement due to education and training of GPs and ongoing support provided to practices. Some practices initially had difficulty uploading the template. Support was provided from the lead GP’s practice.</td>
<td>How do participants enact a practice? Follow protocol. Enlist support from GP Cancer Lead when necessary.</td>
</tr>
<tr>
<td></td>
<td>How does it hold together in action? All GP Practices referring to service. Radiology coping with demand and feel that the service is worthwhile</td>
<td>How do they decide on engagement and the purposes that it serves? Discussions around value to the patient, value to the GP practice. Consideration of additional workload and subsequent impact on capacity. Project driven by the GP Cancer Lead supported by the CCG Quality Manager and wider Steering Group</td>
<td>How are their activities structured and constrained? GPs are responsible for the inclusion of details on the e-referral form. Radiology are responsible for providing advice within a specified timescale, the tests are then booked within 2 weeks and the results are sent to the GP. Cancer patients are upgraded to the 2WW pathway.</td>
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<td></td>
<td>How do participants appraise a practice? Appraisal and feedback encouraged via the steering group and regular contact with the GP Cancer Lead. SurveyMonkey survey sent to all GP Practices. Steering group continues with a wider remit (Wave 2).</td>
<td></td>
<td>How are their effects of appraisal? Appraisal has resulted in changes to the way the GP Lead approaches practices to support the pathway. Appraisal has also led to the steering group putting together a bid for ACE Wave2, which utilises some of the wave 1 data.</td>
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D.2 Chesterfield Royal Hospitals NHS Foundation Trust Primary Investigation Clinic

The following case study describes the processes involved in the Primary Investigations Clinic. The clinic is ongoing and this qualitative evaluation, which used a Realist approach, covers the period to August 2016. The clinic has been running since 2010 and the evaluation was carried out between July 2015 and August 2016.

D.2.1 Introduction and background

Chesterfield Royal Hospital provides services to an area covering a population of around 416,000. This includes the towns of Chesterfield and Bolsover as well as more rural areas of Derbyshire.

Within the borough of Chesterfield, health is varied. In the most deprived areas life expectancy in 10.1 years lower for men and 7.8 years lower for women than in the least deprived. Rates of smoking, obesity and diabetes are higher than the national average for England, as is the mortality rate from cancer for people aged under 75 years.

Chesterfield Royal Hospitals NHS Trust reports that three patients present each week with metastatic malignancies of undefined origin, where the primary cancer site is not clear on presentation. These patients have previously not had a clear pathway for investigation and management. This resulted in them experiencing long stays and uncoordinated care. Many of them require palliative care.

Recent NICE guidance (Metastatic malignant disease of unknown primary origin in adults: diagnosis and management) has recommended that the pathways for patients with metastatic malignancies of undefined origin should be improved.

D.2.1.1 Aims and Objectives

The aim of the clinic was to ensure that patients presenting with cancer where the primary site is unknown had access to the effective pathways that cover the range of care needed including palliative care where appropriate. The objective was to develop a service with a holistic approach that took into account the patient’s and family’s needs.

The intended impact of the clinic was to:

- Streamline the care of patients presenting with cancers of unknown primary site
- Reduce admissions and length of stay.
- Reduce unnecessary testing.
- Reduce delay to specialist palliative care.
- Improve access, communication and advice for general practitioners – clinic directly bookable via Choose and Book.
- Improve patient experience.

The Primary Investigations team consists of:

- Palliative physician
- Oncologist
- Palliative care specialist nurse
• Unknown primary specialist nurse
• Unknown primary multidisciplinary team (surgeon, physician, radiologist and pathologist)

The clinic was designed to streamline the care of these patients who are suspected of having a cancer of unknown primary (CUP) and over time widened to include those with vague symptoms. It was adopted as an ACE project even though it was an established service, because it had the potential to provide support and learning to other newly developed projects and also develop the service through shared learning. No funding was provided through ACE.

D.2.1.2 Clinic Background and Model

The Primary Investigation Clinic was set up in 2010 in response to an audit of 14 patients presenting to the hospital who were diagnosed with cancer of unknown primary (CUP). This case review by the lead nurse and physician showed that there were flaws in the current systems and that patients were not receiving appropriate care in a timely manner (James, 2007). It highlighted the lack of appropriate care for some of these patients and the need for a streamlined pathway to direct patients promptly to appropriate treatments. The audit established the extent of the problem and provided the evidence to convince managers that a new clinic needed to be set up. At around the same time the NICE guideline group on CUP was established and as a result of the audit work both the lead physician and lead nurse successfully applied for positions on the group. NICE guidance was therefore influenced by and in turn influenced the work at Chesterfield.

A second consequence of the initial audit was that Macmillan Cancer Support provided money for a scoping project that established the need for the clinician and CNS posts. As a result of this scoping exercise, a clinic to which GPs could directly refer was set up. While the grant also enabled the clinic to be set up, it did not provide funding for its continuation.

The clinic sees inpatients as well as receiving referrals from GPs directly through a 2 week wait (2WW) referral. It is designed for those patients who have metastatic malignancies on diagnostic imaging, but have no localizing ‘red flag’ signs or symptoms that would permit a site specific referral.

D.2.2 Methodology

The qualitative evaluation of the ACE programme draws on the principles of realist evaluation (Pawson and Tilley, 1997) to develop a contextualised account of the way in which change emerges. See section 2.1 for details of realist methodology. For the purposes of this case study, a total of 13 1:1 interviews with key informants were carried out.

Analysis of the interviews resulted in the development of a Context, Mechanisms and Outcomes (CMO) model (figure 7)
The CMO model considers the contexts, mechanisms and outcomes that were apparent in the implementation of the initiative. Each of the key mechanisms is considered in turn within the case study.

**Figure 7 - CMO model for Chesterfield Royal Hospital NHS Foundation Trust Carcinoma of Unknown Primary Clinic**

**D.2.3 Contexts, Mechanisms and Outcomes (CMO)**

**D.2.3.1 Reassessment of staffing capacity and skills (Ma)**

**Context and Mechanisms**

The primary investigation clinic was initiated by a single lead clinician with a background in palliative care and was already established at the start of the evaluation period. However there were problems with cover for the lead physician. When the clinic was established there was no business case in place for the ongoing staffing of the clinic. The lead clinician’s role developed to lead the clinic and although he was supported by palliative care registrars, they rotated every year. As their background was in palliative care, the primary investigation clinic model was new to them. Coupled with the short term nature of the position, this meant that they were lacking in confidence to run the clinic when the lead clinician was on leave, leading to potential staffing issues.

‘*Usually by a few months they were confident, but it would meant that in the first couple of months of having a registrar I probably wouldn’t be away on a clinic day*’

Lead Clinician

The lead clinician was supported by a specialist nurse who could act as a key worker for the patients coming through the clinic. At the start of the project, one specialist nurse was in position on a secondment basis, by the time the final interviews were
completed the post had been made substantive. As with the lead physician, this led to issues with cover.

**Characteristics of mechanisms and outcomes**

Training was provided to increase the confidence of the registrars in running the clinic and using the resources of the multidisciplinary team effectively, such that the clinic could be held even when the specialist was not there.

‘They’re coming from a place where the palliative care registrars haven’t been doing unknown primary clinics. And I always say to them well actually you’ll be surprised at how you find it meets your skill set. And they say well I don’t know about diagnostics. And I say well you are not alone, you’ve got a team and that’s what the team are there for ....usually by a few months they were confident’

Lead Clinician

‘So even his quite junior registrars would be capable of running a clinic in his absence, and certainly getting the right tests initiated and that sort of thing. So the clinic never stops for his absence’

Lead Nurse

The concerns about consultant cover were further relieved by the appointment of consultant cover during the course of the evaluation period.

While initial concerns regarding consultant cover and registrar training were overcome, nurse capacity and skills remained a concern. While having a dedicated nurse was seen as an effective way of working and felt to be one of the successes of the programme, the lack of nurse capacity was still an issue at the end of the evaluation period.

‘And the issue we do have is obviously the CNS doesn’t have cover. So that clinic doesn’t have a nurse in when that nurse is away. And for any thing unanticipated, sickness, annual leave, is obviously an issue’

Lead Nurse

Nevertheless, funding had been gained for additional nursing cover, but the position had not yet been filled.

‘We now have [got funding] but it’s just been a frustrating wait, really and for some reasons it’s not gone out to advert yet. It’s all ready to go and I’m still waiting for it to go out’

Lead Clinician

Being able to provide cover for the CNS role was important, not just to cover leave and sickness absences, but also to allow for training. While there was an established training programme for registrars, this was not the case for the nurse. There was a local course to train palliative care CNSs and while this had some overlap with the primary investigation clinic role, there were areas of training that needed development. As there was only the one specialist nurse in post, this resulted in lack of cover, making it difficult for her to attend training and limited her opportunities for peer support and associated skill development.
‘Some will say well I can’t do training days because if I’m not going to be here, they will not want to pay £4-5-600 out are they’

Specialist Nurse

Interpretation

Due to the way the clinic was initially set up and funded, there were problems with staff capacity and skills. Developing staff skills through training is an important factor in allowing clinics to run efficiently and provide cover when lead staff are absent. That capacity is also needed to allow staff to attend training without affecting the running of the clinic.

D.2.3.2 Leadership (Mb)

Context and Mechanisms

Overall leadership came from the lead clinician and the lead GP. The lead clinician drove the initial implementation of the clinic and acted as the leader within the Trust and also promoted the model on a national basis. The Lead GP led in the promotion of the primary investigation clinic model on a local, regional and national basis, and was particularly influential in promoting the model with commissioners and the regional Strategic Clinical Network.

Characteristics of mechanisms and outcomes

The project successfully engaged the different professional groups because the clinical lead was seen as credible by them. As a palliative care physician and general physician, he was able to raise the profile of palliative care. As he had previously worked in primary care, he was also seen as understanding some of the problems faced by GPs, giving him additional credibility.

‘Yeah, he hasn’t done primary care for a long time and he wasn’t that experienced when he went sideways into palliative care, but at least he has that grounding and he understands about how primary care works more than most, so I think that certainly is a good thing’

Lead GP

Several people noted that there were potential problems around sustainability with a project that was being driven by one individual. However, in the course of the evaluation period, staff and finances were put in place to ensure its sustainability.

‘I actually I have said to him on more than one occasion, if you were to leave tomorrow what would still manage to run?... If you moved on tomorrow could we still run this clinic and extend this clinic? Now he very much insists yes, he thinks he’s got the people around him and the second consultant that he thinks he could’

Lead GP

The lead GP promoted the model through the ACE cluster group meetings and it was successfully implemented in some neighbouring areas.
Interpretation

The successful leadership of this project was attributable to the personalities of two key individuals, their commitment to quality improvement and their credibility with their peers and other professional groups.

D.2.3.3 Connections and Communications between professionals (Mc)

Context and Mechanisms

The Primary Investigations clinic was conceived and implemented by a single clinician, but brought together professionals to develop a multidisciplinary team that could provide support.

“I’ll take responsibility as long as we can have a segment of the MDT that is unknown primary, and that we needed the radiologists and the histopathologist to be there for that. But in fact everyone stayed for it. So we have a GI physician and two GI surgeons, the upper GI nurses stay as well. And sometimes we have the hepatobiliary surgeon from Sheffield comes as well, which is very useful. So we have got a full MDT’

Lead physician

Communications with local GPs was an important mechanism in the implementation of the clinic. Clear guidelines were developed and circulated to GPs within the catchment area of the Trust.

“We made sure we put out a very succinct guideline and a letter to all the practice managers, all the GPs’

Lead GP

As the awareness of the clinic in the area grew, interest from other areas developed and meetings and discussions were held between professionals in the Chesterfield CUP clinic and other areas interested in developing their own local services.

Characteristics of mechanisms and outcomes

The GP lead was proactive in working with local GPs to promote the primary investigation clinic. The communications with local GPs resulted in increased understanding of the role of the clinic. As the awareness of the clinic grew, referral numbers increased. Having the ability to ring and ask for advice also allowed GPs to manage some situations in primary care where appropriate, or refer on the most appropriate pathway.

“A lot of GPs will ring in just for advice first before they actually refer’

Specialist nurse

The GP lead was proactive in promoting the service regionally and nationally through the ACE cluster meetings. As a result of discussions and sharing learning and experiences with other areas, a number of similar models are being developed in other local areas such as Doncaster.
Interpretation

Effective connections and communications between professionals within the hospital have increased the use of the clinic. Work communicating the role of the clinic to GPs who will be referring was important in raising awareness and utilization. Sharing learning with other groups has helped to set up other similar clinics.

Links developed through local organisations and the cluster groups allowed the Chesterfield group to share their experience and provide guidance to other groups setting up their own similar projects.

D.2.3.4 Audit of current practices (Md)

Context and Mechanisms

The clinic was set up as a result of an audit carried out by the lead nurse and clinician in 2010. Yearly audits of the clinic’s activity have been carried out since then.

Characteristics of mechanisms and outcomes

Ongoing audit has examined time from referral to being seen in clinic, to diagnosis and to start of treatment, along with diagnosis, treatment and survival. It has identified where problems and delays in the pathway were occurring and has helped to refine the service.

’Some of the audits we did would show that patients were referred quite late in the patient’’ pathway. So I think there’s always lessons to be learnt’’

Lead Nurse

Patient experience surveys have been also been done although it proved difficult to collect data.

’I know I did a patient experience survey…..Very small numbers and very difficult because actually the patients that were true unknown primary could have quite a poor prognosis and actually may have passed away….it’s a very difficult group to gather their experience. It’s easier to get patient quotes’’

Lead Nurse

Interpretation

The audit allowed staff to understand of the problem of identifying and managing patients with cancers of unknown primary. Audit provided the impetus to establish the clinic and ongoing audit help develop understanding of the pathway and its capacity requirements.
D.2.3.5 Resources (Me)

Context and Mechanisms
Short term funding allowed the clinic to be established, but did not provide resources for the ongoing service. This created problems with sustainability of the service as there was a lack of funding for cover for key positions. The clinic was adopted as an ACE project with no additional funding at the time.

Characteristics of mechanisms and outcomes
At the start of the evaluation period the clinic was running without being fully resourced. The Trust have since provided the extra resources to increase staffing capacity and overcome the continuity problems that had arisen from running an under-resourced service. The ACE label helped provide some create recognition of the importance of the service within the Trust.

‘In terms of development it is the recognition of the service that has enabled the securing of cover for the nurse role....So yeah getting recognised, I think is that we’re seen as an essential service which can’t just run on a shoestring’

Lead clinician

ACE wave 2 funding was applied for to develop a virtual MDC, however this was unsuccessful and ways to find the resources to undertake this work are being explored.

Interpretation
Funding from Macmillan Cancer Support helped establish the need for the clinic but provided no ongoing support, creating problems with resources to run a sustainable service. ACE provided no additional funding, but provided the service with the credibility needed to prompt the Trust to find additional resources.

D.2.4 Conclusions
The outcomes specified in the CMO table (figure 7) were evidenced in the following ways:

O1. Faster route to diagnosis – there are a number of anecdotal cases where patients have received faster care. Having the specialist nurse as a key worker who can chase testing and be a contact point for patients ensures that correct tests are done and appropriate information is passed on.

O2. Sustainability – This was initially an area of concern due to lack of cover for consultant and specialist nurse. The consultant cover has been addressed and funding for cover for the specialist nurse has been found, however appointments have not yet been made. The service has moved towards become more sustainable through the course of the evaluation.
O3. Patient experience – There are a number of anecdotal reports of patients and family reporting that the care received was appreciated. Audits and patient experience surveys back these reports.

‘I’ve had a lovely lady this morning that’s ring me about her aunty that’s died with us and she just couldn’t praise everybody enough’

Specialist Nurse

O4. Raised profile of palliative care – there is evidence that the palliative care team is much more visible in the hospital as result of the CUP clinic, and people are being referred when appropriate.

O5. Spread of model to other local areas – similar models have been adopted in other areas.
D.3 London Cancer - University College London Hospital MDC pilot

*London Cancer* was formally established in 2012 as the integrated cancer system across north central and east London and west Essex. It serves a population of over 3.2 million.

*London Cancer* brings together 11 NHS provider organisations, the voluntary sector and 4 academic partners. The integrated cancer system is clinically led, with responsibility for delivering specified care pathways for different tumour sites and for delivering safe and effective care for the populations they serve.

For the ACE initiative, *London Cancer* identified two sites to pilot the concept of a Multidisciplinary Diagnostic Centre (MDC), which aimed to provide a more structured diagnostic pathway for patients with abdominal symptoms. The sites chosen were University College London Hospital and Queen’s Hospital in Romford.

The following case study describes the ongoing processes involved in implementation of the project at University College London Hospital. The project is ongoing and this qualitative evaluation covers the period to July 2016.

D.3.1 Introduction and background

University College London Hospitals NHS Foundation Trust (UCLH) is a complex organisation, serving a large and diverse population. They provide academically led acute and specialist services to people from the local area, from throughout the United Kingdom and overseas. The Trust has contracts with Clinical Commissioning Groups from all over the country to provide a range of services to their populations. There are over 950,000 outpatients and admit over 156,000 in-patient admissions each year. Within central London, University College London Hospitals Trust delivers services from a range of locations including; University College Hospital, Macmillan Cancer Centre linked to UCLH, the Elizabeth Garrett Anderson Wing and the Hospital for Tropical Diseases. Prior to the implementation of the ACE project, UCLH had already gained significant experience of cancer pathway redesign and implementation of improvement initiatives. For central London, The ACE project was delivered from the UCLH site, with initial consultations being conducted in the Macmillan Cancer Centre.

D.3.1.1 Aims and Objectives

The 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 intention was for data collected during the pilot to be used to refine the operational and clinical criteria for managing vague abdominal symptoms and promote earlier diagnosis of cancer.

More specific objectives were to:
• Provide patient and GP access to rapid specialist assessment, diagnostic tests and a management plan within a few days of referral
• Evaluate both non-specific, “grey area” symptoms, severe enough to warrant early attention but which did not qualify for a 2 week wait (2WW) referral and also specific 2WW symptoms to demonstrate improved metrics of this pathway
• To measure patient experience during the process to assess the effectiveness in addressing fragmentations of the previous diagnostic pathway.
• To use the data collected to inform future service development and planning

**D.3.1.2 Ace Model**

The MDC will receive referrals from GPs and Emergency Departments (ED) for patients fulfilling the following criteria:

• Painless jaundice – either clinically obvious or bilirubin>80, cause unknown
• Weight loss – more than 5% recent, unexplained and proven weight loss; not previously investigated and with no likely benign diagnosis
• Suspicious but non-specific abdominal symptoms, these should have lasted >3 weeks but < than 6 months, and malignancy suspected in the differential
• Recurrent abdominal pain – resulting in at least 2 visits to the ED or primary care within 1 calendar month, not previously investigated and without a likely diagnosis.

![Figure 8 Pathway for London Cancer Alliance MDC](image-url)
In the case of UCLH, a Clinical Nurse Specialist conducted the clinical triage undertaken in the MDC.

**D.3.1.3 Project Scope**

The project was to run as a one year pilot period and started in June 2015.

**D.3.1.4 Implementation**

*London Cancer* had an experienced Quality Manager with substantial NHS and clinical experience, project managing and leading the project. The Quality Manager was a dedicated role focused on supporting clinicians and managers at UCLH and at Queens Hospital, Romford, to get the project up and running, address problems and support the embedding and sustainability of the project. In addition a steering group including key stakeholders from UCLH was established to ensure that operational and governance issues were addressed. Local leadership came from a Lead Gastroenterologist based at UCLH.

**D.3.2 Methodology**

The qualitative evaluation of the ACE programme draws on the principles of realist evaluation (Pawson and Tilley, 1997) to develop a contextualised account of the way in which change emerges. See section 2.1 for details of realist methodology. For the purposes of this case study, a total of 17 1:1 interviews with key informants were carried out.

Analysis of the interviews resulted in the development of a Context, Mechanisms and Outcomes (CMO) model (figure 9)

The CMO model considers the contexts, mechanisms and outcomes that were apparent in the implementation of the initiative. Each of the key mechanisms is considered in turn within the case study.

Normalisation Process Theory (NPT) provides the theoretical basis for understanding how the initiative is understood, implemented and embedded into normal practice. NPT considers four areas; coherence, cognitive participation, collective action, and reflexive monitoring. See section 2.2 for details. Each of these areas are considered in turn in table 8.
N.B. We do not specifically discuss the second mechanisms cluster M1-M7 because they are components of the mechanisms discussed Ma-Mf.

D.3.3 Contexts, Mechanisms and Outcomes (CMO)

D.3.3.1 Service/Pathway design (Ma)

Context and Mechanisms

London Cancer identified that patients experiencing vague abdominal symptoms often did not have a smooth diagnostic pathway. In addition an A&E audit indicated that UCLH and other London Cancer hospital sites had a large proportion of patients with cancer presenting via A&E. This in conjunction with some stakeholder events led to the suggestion of developing a Multidisciplinary Diagnostic Centre.

UCLH were motivated to work with London Cancer to develop the concept of an MDC because it built upon previous cancer pathway redesign work and because its organisational culture was one which was proactive and receptive to change.

A proposed pathway for patients with vague abdominal symptoms was developed by London Cancer; UCLH reviewed it and adapted it to fit their own organisation, actively supported by a Project Manager from London Cancer. The Gastroenterology Lead Clinician at UCLH led the project focusing on a MDC approach for patients presenting with vague abdominal symptoms.
Characteristics of mechanisms and outcomes

The pathway was developed by the Gastroenterology Lead Clinician, the Superintendent Radiographer, Clinical and Administrative Managers and the Matron for Gastroenterology in conjunction with the London Cancer Quality Manager (see fig 8 for detail), a Clinical Nurse Specialist role was developed to provide the initial point of contact for the patient, and to give ongoing support for the patient whilst on the pathway.

The pathway went live in mid-June 2015

The development of the MDC involved a number of stages including; developing a project plan, engaging with stakeholders, establishing a steering group, identifying monitoring metrics and provision of day to day leadership and support, all of which were supported by the London Cancer Project Manager. The pathway was similar to the one initially developed by London Cancer except that a Clinical Nurse Specialist was the first point of contact and the pathway would be delivered in an outpatient setting.

Referral forms were developed; patients were referred directly from primary care to the MDC, with referral forms being emailed through to an administrator:

“"So we’ve got a proforma which will be emailed through to an administrator and then an appointment is then given within 24 hours. We’ve produced a leaflet explaining what the clinic involves, and that the patients are likely to have tests as soon as they come up, who they will see and what will happen to them over the next few days”.

Lead Clinician

The leaflet given to patients explaining the purpose of the clinic was developed in collaboration with key stakeholders:

“And that leaflet has been put together with a combination of XX (Project Manager), myself, YY, who is our manager and ZZ, who is the GP lead, to make sure everybody’s happy with it”

Lead Clinician

When the patient attends the Macmillan Centre an initial assessment is conducted by the Clinical Nurse Specialist (CNS). Blood tests are taken as soon as the patient arrives, with the results being available rapidly in order to assist the decision about the most appropriate test:

“So some of those bloods will be available within half an hour, really to guide the next test – because if we’ve somebody with abdominal symptoms and iron deficiency anaemia, for example, we’d be pushing them down the endoscopy or colonoscopy route rather than necessarily a CT”

Lead Clinician

Patients requiring a CT scan received one within 24 hours with slots ring fenced for this purpose. Urgent slots for endoscopy were also identified. Because UCLH is a tertiary centre their department of Gastro-intestinal (GI) Medicine is subdivided into pancreaticobiliary, colorectal and upper GI. Once the initial results were available, the patient was referred to the clinic of the most appropriate gastroenterologist:
“Once the patient has been seen (by the CNS), had the initial assessment, had their scanning or scopes done, they’ll then be seen by the most appropriate consultant. So rather than have a general gastroenterologist they’ll be straight in to a specialist appropriate clinic”

Lead Clinician

Anecdotally, patients appeared to like the pathway:

“We’ve had some really positive feedback from patients, they like how quickly they get seen, investigated and get a diagnosis”

Clinical Nurse Specialist

“We’ve had informal patient feedback and patients appear to like the service because it’s quite personal and quick”

Lead Clinician

A formal patient satisfaction survey has been conducted by an intern working for London Cancer, which used telephone interviews to assess patient experience. We were told that the vast majority of those interviewed were happy with the care they received.

Interpretation

Because patients go straight to the most appropriate specialist rather than a general gastroenterologist there was the potential to fast track patients to the correct Cancer Multi-Disciplinary Team (MDT) if required, further reducing any unnecessary waits.

D.3.3.2 Steering Group (Mb)

Context and Mechanisms

In order to deliver the project within the identified one year timeframe a steering group that included managers and clinicians from GI Medicine, Radiology, Primary Care and London Cancer was established in the planning stages of the project. Involving individuals who would use and deliver the service in the steering group also helped ensure ownership of the project and the changes required to deliver it.

Characteristics of mechanisms and outcomes

The steering group met regularly, initially to map existing pathways, develop the new pathway, and agree evaluation metrics and latterly to monitor and review progress. The steering group dealt with both operational and strategic issues. It was viewed to be effective by interviewees:

“It’s been really useful because we are all there with a common aim and understanding of what we are trying to achieve and that’s meant when issues arise it’s much easier to resolve them”

Superintendent Radiographer

“I think it was really useful being involved in the steering group because it helped us to get to know other key people involved in the project at an early stage, allowed us
to build relationships that we didn’t previously have but turned out to be really useful once we were up and running dealing with day to day problems, teething problems. It’s always better to put a name to a face and to understand their role in the process and for them to understand yours”

GI Medicine Service Manager

Performance management and pathway evaluation was also a function of the steering group, with the London Cancer Quality Manager regularly tabling reports highlighting progress against the following agreed metrics:

- Number of referrals
- Number of GP practices referring to the service
- Number of patients receiving definitive diagnosis
- Number of patients receiving diagnosis of cancer
- Percentage of patients offered first appointment within one week of being referred by GP

**Interpretation**

One of the reasons the steering group was successful was that it was formed during the early planning stages of the project and included membership from all of the areas which could be impacted by the pathway. These people were identified in an initial stakeholder mapping exercise and not brought in as an afterthought when the planning processes were well developed; this was something which on an individual basis they appreciated.

UCLH is a large and complex organisation and a number of interviewees commented that individual teams/departments operated in relative silos. This project had been different, bringing together people who would not normally work closely. Interviewees felt that an unanticipated benefit of the steering group was that some members had a much better understanding of other departments and their work than previously.

**D.3.3.3 Identification of staffing needs (Mc)**

**Context and mechanisms**

In order to deliver the one year project a CNS whose role was to support patients with benign biliary disease was initially co-opted to provide the CNS input into this pathway, in conjunction with another CNS whose role was with cancer patients, supporting them through diagnosis and treatment.

The new role of the MDC Pathway Co-ordinator was also viewed as essential to making the pathway work. This was a patient-facing administrative role.
Characteristics of mechanisms and outcomes

The CNSs were initially anxious about being the first point of patient contact for the new pathway, but the informal education and support provided by the consultants helped them to develop their skills and confidence:

“I was a bit concerned about well who is going to make those decisions (regarding investigations), you know, not me, but obviously I need to get enough information for the consultants, whoever they may be, to have the information to make clinical decisions. But having had quite a lot of discussion with one of the consultants here, who’s very pro the project, I feel more reassured that I will get support and I am quite confident about taking a history etc.”

Clinical Nurse Specialist

As the pathway became more embedded the CNSs also exhibited more confidence in their ability to conduct the initial assessment:

“Yes, I’m happier now about doing the initial assessment, the consultants are always there for advice and back up should it be needed and the more patients you see the more your skills develop”

Clinical Nurse Specialist

The MDC Pathway Co-ordinator is an administrative role responsible for receiving the referrals, allocating the patient to a CNS clinic appointment, ensuring investigations are ordered and reports available and that the patients subsequently receive a specialist clinic appointment. The MDC Pathway Co-ordinator also meets the patient when they arrive at their initial appointment and initially helped them complete a medical questionnaire on a tablet computer. This latter task ended when use of the questionnaire was suspended due to patients not liking it and technological problems with the tablet computer. The role also involves data collection and tracking:

“So I’ve got a spreadsheet where I keep each patient and dates of referral, dates they were first seen, dates of the scans and then I have a comment section at the end . . . where I just update that when information comes through. So that’s my way of keeping track of what’s going on with each patient.”

MDC Pathway Co-ordinator

The MDC Co-ordinator role appeared to work well and was valued by colleagues:

“RR’s role has been really valuable, she has good interpersonal skills and does more than stated in the job description, so things like some-one ring to say they don’t want to attend, she’ll proactively manage that potential DNA and encourage them to attend in a timely manner.”

Cancer Quality Manager

“The MDC Co-ordinator has been really helpful, once we worked out areas of role overlap and who had responsibility for what she has been great in terms of chasing things up and making things happen on our behalf”

Clinical Nurse Specialist
The MDC Pathway Co-ordinator left her post prior to the end of the evaluation period. At first, temporary staff were brought in to cover the role, this proved to be problematic and protocols were not rigorously followed. The role was then divided amongst a number of experienced existing administrative staff and overseen by the Service Manager. This was reported to work well as a short term solution; however the post was being advertised at the time the final interviews were being conducted.

**Interpretation**

The support and training provided by the consultants has been essential to the success of CNS role particularly in the early stages of pathway implementation when systems and processes were also being tested. The MDC pathway co-ordinator role was also shown to be important in the efficient running of the pathway, as the absence of the co-ordinator proved to be problematic.

**D.3.3.4 Evaluation of capacity: staffing, time and space (Md)**

**Context and mechanisms**

In order to ensure delivery of the project within the one year specified timescale capacity was reviewed at the outset. Existing space and CNS availability were limited and additional capacity had to be found.

Additional nursing capacity was initially provided by two existing CNSs (see previous section for more detail). Initially, the pilot anticipated about ten patients per week, so CT capacity was modelled on that basis.

UCLH is a busy hospital where finding space to hold new clinics is a challenge, so space was identified in the Macmillan Centre, a modern building in Huntley street, separate to the main UCH block.

**Characteristics of mechanisms and outcomes**

The model of the CNS being the first point of contact worked well but there were some initial challenges linked to CNS availability:

“I think the only challenge has been CNS availability. That has been the only problem. That’s the only thing that perhaps would set back a patient being seen the next day, and that’s no fault of their own, that’s just because they have such a big workload themselves and this is an additional thing that they’re doing. I think that will improve when KK starts (designated CNS for the pathway)”

MDC Co-ordinator

By the end of the evaluation period one of the initial CNSs had changed role and the second was unable to continue supporting the pathway due to her other clinical commitments. An additional post holder was appointed to focus on supporting the pathway with back fill for annual leave and training provided by colleagues.
Radiology capacity was not considered an issue because they had identified an additional CT slot per day and had the ability to access other unfilled slots as necessary.

“From my point of view it went exactly as we thought. We had the capacity. We get a phone call in the morning; we just fit them in at short notice, either that day or the following day,” Superintendent Radiographer

Space was identified in the Macmillan Cancer Centre for the MDC. There were some concerns that this might create patient anxiety because of the building’s name, and the steering group felt that it was important to stress to patients that the pathway was aimed at ruling out cancer, only in a small number of cases confirming a cancer diagnosis:

“So we’ve identified space in the Macmillan Centre. And there was a little bit of concern about the fact that that’s got cancer in the name, so we have put in the leaflet that lots of people are seen at the Macmillan Centre who don’t have cancer” Lead Clinician

Anecdotally, interviewees reported that patients found the clinic location acceptable and that a number of patients had provided comments on its relaxed, less clinical environment.

Interpretation

As well as ensuring nursing capacity, having one CNS instead of the role being split between two individuals also helped to facilitate the development of expertise and provide continuity for the patients.

The radiology service was able to respond to the changing needs of the project, partly because it did not have any major capacity pressures and because it had a proactive manager who was engaged with the steering group.

Having an appropriate physical space was a factor in being able to run the clinic effectively. While the name of building raised concerns it did not appear to affect patients’ perceptions of the clinic.

D3.3.5 Connections and communication between professionals (Me)

Context and mechanisms

There was agreement across a range of stakeholders including primary, secondary care and London Cancer that there were problems in diagnosing cancers that present with “vague symptoms”, and that there were too many patients attending A&E who were poorly served by the existing clinical pathways. There was a consensus that something new needed to be piloted to try and address these issues.
Characteristics of mechanisms and outcomes

Internally within UCLH much of the communication occurred within the steering group, with the stakeholder members of the group expected to relay consistent information to their own constituencies, interviewees reported that this approach worked well and a variety of formats were used including emails, newsletters and feedback at a range of meetings. When necessary, it was supplemented by having a weekly “huddle” where clinicians and managers met to discuss progress with the MDC which also reportedly worked well.

The pathway was detailed within some GP newsletters and also in the UCLH newsletter. There was some anecdotal evidence that this helped raise general awareness of the pathway. UCLH as an organisation also highlighted the MDC as an area of good practice:

“The other success was, probably now UCH is celebrating that they’re doing MDC. We made it on to their internal monthly dashboard”

Cancer Quality Manager

The Lead Clinician also did some educational events with the GPs which were particularly effective in raising awareness with the GPs and encouraging them to refer using the pathway:

“SS (the Lead Clinician) has done two GP events for us. One which was more like a lecture but the second was a form of speed dating. The speed dating was amazing. We’ve got a graph actually showing we had a spike of referrals after she went to meet them. It was an opportunity to speak face to face with the GPs, giving them space to ask questions, they really appreciated that.”

Cancer Quality Manager

Interpretation

The importance of the need for providing consistent messages in a range of formats across stakeholder organisations is vital if all stakeholders are to be kept informed. Face to face contact between consultants and GPs was particularly valued and resulted in increased referrals.

D3.3.6 Supporting Technology development (Mf)

Context and mechanisms

London Cancer supported the development of an electronic symptom questionnaire by an independent start-up company. The intention was that it would aid clinical assessment.

Characteristics of mechanisms and outcomes

The intention was for the questionnaire to be administered in an electronic format (tablet computer) when the patient presented for their first appointment, prior to
being seen by the nurse. It was found that elderly patients did not like using the tablet and so the MDC Pathway Co-ordinator assisted them in completing it. Feedback from the patients indicated that it was too lengthy and as a result it was amended on a number of occasions, however patients still reported disliking it:

“We did have that questionnaire, the electronic questionnaire but patients actually don’t like it”  Lead Clinician

In addition, there were a number of project management issues related to the development of the questionnaire which on occasion prevented the London Cancer Quality Manager (who was project managing the whole ACE project for UCLH) from focusing on ensuring that the pathway was being implemented as planned and that the protocols and standard operating procedure were robust.

Prior to the end of the evaluation period use of the tablet questionnaire was discontinued.

**Interpretation**

The development and use of the questionnaire appears to have been a separate project nested within the ACE project. Although it had been piloted at another site prior to use in the ACE project, it may have been more successful had more development and piloting work been done prior to the implementation of the ACE project as it became an irritation for patients and a distraction for the project manager.

**D.3.4 Conclusions**

The outcomes specified in the CMO table (figure 9) were evidenced in the following ways:

O1 Faster route to diagnosis - there is a perception that often these patients were being sent for wrong diagnostic tests initially, leading to delays in diagnosis or managed in primary care for an unnecessary amount of time. Feedback from GPs to the project lead indicates that they do feel this is a faster route to diagnosis for cancer and non-cancer patients. There is no evidence from the interviews that this pathway has resulted in earlier detection of cancers although there is a perception that some patients have been to clinic who might previously not have:

“But I think we have started seeing some patients that might not have been referred without the existence of this pathway”  Cancer Quality Manager

There is also a perception amongst interviewees that prior to the MDC pathway often these patients were being sent for wrong diagnostic tests initially, had to wait a significant period of time before they had scans or scopes which ultimately led to delays in diagnosis.

O2. Understanding of staffing/roles/ capacity needs – interviewees state they understand capacity better in relation to this service although the fluctuating
demand initially was something they found frustrating, however demand has stabilised since more GPs are consistently referring to the service.

O3. Detection of diseases other than cancer - anecdotally, the vast majority of patients seen via this route have diseases other than cancer and once cancer is ruled out they are placed on an appropriate pathway or reassured and referred back to the GP.

O4. Sustainability – the project has been mainstreamed within UCLH (see NPT table 8 for further detail), and funding for the ongoing provision of the service has been agreed.

O5. Use of technology to understand presenting symptoms and aid clinical diagnosis – the patients did not like the questionnaire and there were practical issues with the technology as a result its use ceased.

O6. Streamline pathway and develop protocols – the evaluation of the pathway was an ongoing process with changes being made as issues arose. Protocols were developed and revised as the project progressed.

O7. Roll out to other centres – The plan is to role this model out across London Cancer as part of the ACE Wave 2 work programme.

O8. Patient satisfaction – it was reported within the interviews that most patients liked the speed with which they were seen and the environment in which they were seen. The telephone survey has also been reported as being positive however the qualitative researchers have not been shown data to support this.

O9. Sharing good practice - learning from this pilot has been widely shared both locally across London Cancer and nationally via the ACE Vague Symptoms Cluster and Wave 2 meetings.

O10. GP confidence – interviewees feel that GPs value you the service, based on informal feedback at GP events and to the GP lead and also by virtue of the fact that they are using the pathway to refer patients with concerning abdominal symptoms.

Applying a Normalisation Process Theory framework to our findings, we conclude that many aspects of this project have been normalised (see section 2.2 for detail on Normalisation Process Theory), these have been analysed using an NPT framework and the results are shown in table 8:
Table 8 - Factors associated with the normalisation of MDC at UCLH

<table>
<thead>
<tr>
<th>Core questions</th>
<th>Coherence</th>
<th>Cognitive participation. Who does the work?</th>
<th>Collective action How does the work get done?</th>
<th>Reflexive monitoring How is the work understood?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systematic explanation of mechanisms and components at work</td>
<td>London Cancer, local CCGs, UCLH and GP practices recognised it as building upon previous cancer pathway redesign work. Education events and regular feedback from the Lead GP and the Project Manager have reinforced the mechanisms of the process.</td>
<td>GPs refer patients with concerning abdominal symptoms. CNS does the assessment, and arranges initial diagnostics. Scans and scopes done within UCLH. Patients are seen by the most appropriate consultant. GPs informed of results. Where findings require it patient moved to appropriate pathway.</td>
<td>Training was provided in relation to the pathway. The CNS was given training and an in-depth induction and ongoing support for provided by the Consultants. The MDC Pathway coordinator was also given training and provided with ongoing supported. Detailed protocols for the pathway were also developed.</td>
<td>Working closely with the steering group helped appraisal of systems and processes by all stakeholders involved.</td>
</tr>
<tr>
<td>Knowledge about the sources and operation of investments at work</td>
<td>All practices understood the mechanism of referring patients and how it linked with the pathway. The education events with the GPs seemed to address these issues.</td>
<td>Value of the intervention was promoted by proponents of the service from London Cancer. There was consensus that the intervention was worthwhile from a patient perspective.</td>
<td>GP practices engaged in referring patients to the MDC. CNS responsible for initial assessment and ordering investigations. Radiology for CT scans. MDC pathway coordinator for booking and following up tests and tracking the patients, also for booking patients into clinic. The consultants see the patients in clinic and manage them accordingly, refer on as appropriate or discharge back to the GP.</td>
<td>There is good understanding of factors affecting the pathway across key stakeholders with the with the Steering group proactively managing issues and continuing to shape and develop the service as it rolls out and as they get an opportunity to scrutinise data.</td>
</tr>
<tr>
<td>How is a practice conceptualised by participants?</td>
<td>Viewed positively by General Practice, London Cancer and providers at UCLH.</td>
<td>Practices were initially approached by the Lead GP and London Cancer Quality Manager. The project was actively supported by the London Cancer, the local CCGs and UCLH. More sustained engagement due to education and training of practices and ongoing support.</td>
<td>How do participants come to engage with a practice? Follow protocol. Enlist support from Project Manager when necessary.</td>
<td>How do participants appraise a practice? Appraisal and feedback encouraged via weekly “huddles”, the steering group and regular contact with the Project Manager.</td>
</tr>
</tbody>
</table>
How does it hold together in action?
Most GP Practices referring to the MDC. The CNS conducting the initially assessment and arranging investigations. Radiology coping with demand for the CT scans. MDC Pathway coordinator role provides administration and tracking function. Most appropriate GI Consultant sees patients in clinic and decides most appropriate ongoing management. Stakeholders feel that the service is worthwhile.

How do they decide on engagement and the purposes that it serves?
Discussions around value to the patient, Consideration of additional workload and subsequent impact on capacity. Project driven by London Cancer, supported by a motivated engaged Lead Clinician and an engaged steering Group.

How are their activities structured and constrained?
Practices are responsible for referring the patients to the MDC. The CNS is responsible for assessing the patients and referring them for investigations. Radiology are responsible for CT scans and reporting. The MDC pathway coordinator deals with administrative and patient tracking issues. Consultants see patients in clinic and decide ongoing management, onward referral or discharge back to GP.

What are its effects of appraisal?
Appraisal has resulted in small changes to the pathway and the discontinuation of the questionnaire. Appraisal has also led to the steering group putting together a bid for ACE Wave2, which utilises some of the wave 1 data.
D.4 London Cancer - Queens Hospital, Romford MDC pilot

London Cancer was formally established in 2012 as the integrated cancer system across north central and east London and west Essex. It serves a population of over 3.2 million.

London Cancer brings together 11 NHS provider organisations, the voluntary sector and 4 academic partners. The integrated cancer system is clinically led, with responsibility for delivering specified care pathways for different tumour sites and for delivering safe and effective care for the populations they serve.

For the ACE initiative, London Cancer identified two sites to pilot the concept of a Multidisciplinary Diagnostic Centre (MDC), which aimed to provide a more structured diagnostic pathway for patients with abdominal symptoms. The sites chosen were University College London Hospital and Queen’s Hospital in Romford.

The following case study describes the processes involved in implementation of a multidisciplinary diagnostic clinic (MDC) at Queen’s Hospital, Romford for patients with abdominal symptoms that could be due to cancer over the period September 2015 to March 2016.

D.4.1 Introduction and Background

Queens Hospital in Romford is a large acute hospital in the London Borough of Havering; it is part of Barking, Havering and Redbridge University Hospitals NHS Trust. The Trust works in partnership with a range of voluntary and statutory organisations in order to deliver care for a diverse community of 750,000 people. The Trust has two acute services providers; Queens Hospital in Romford and King George Hospital in Goodmayes. The ACE project was delivered from the Queens Hospital site.

D.4.1.1 Aims and Objectives

The 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 intention was for data collected during the pilot to be used to refine the operational and clinical criteria for managing vague abdominal symptoms and promote earlier diagnosis of cancer.

More specific objectives were to:

- Provide patient and GP access to rapid specialist assessment, diagnostic tests and a management plan within a few days of referral (14 days was the initial target)
- Evaluate both the pathway for non-specific, “grey area” symptoms, severe enough to warrant early attention but which did not qualify for a 2 week wait (2WW) referral and also that for specific 2WW symptoms, to demonstrate improved metrics of this pathway
- To measure patient experience during the process to assess the effectiveness in addressing fragmentations of the previous diagnostic pathway.
To use the data collected to inform future service development and planning

**D.4.1.2 ACE model**

The MDC would receive referrals from GPs and Emergency Departments (ED) for patients fulfilling the following criteria:

- Painless jaundice – either clinically obvious or bilirubin>80, cause unknown
- Weight loss – more than 5% recent, unexplained and proven weight loss; not previously investigated and with no likely benign diagnosis
- Suspicious but non-specific abdominal symptoms, these should have lasted >3 weeks but < than 6 months, and malignancy suspected in the differential
- Recurrent abdominal pain – resulting in at least two visits to the ED or primary care within one calendar month, not previously investigated and without a likely diagnosis.

![Diagram](image)

**Figure 10 London Cancer Alliance MDC pathway**

The first point of contact was to be a Gastroenterologist with the service being delivered in an outpatient setting.

**D.4.1.3 Project Scope**

The project was to run for a one year pilot period and started in September 2015

**D.4.1.4 Implementation**

London Cancer had an experienced Quality Manager with substantial NHS and clinical experience, project managing and leading the project. The Quality Manager
was a dedicated role focused on supporting clinicians and managers at both Queens Hospital and UCLH to get the project up and running, address problems and support the embedding and sustainability of the project. In addition a small steering group including key stakeholders from Queens Hospital was established to ensure a range of operational and governance issues were addressed. Local leadership came from a Lead Gastroenterologist.

**D.4.2 Methodology**

The qualitative evaluation of the ACE programme draws on the principles of realist evaluation (Pawson and Tilley, 1997) to develop a contextualised account of the way in which change emerges. See section 2.1 for details of realist methodology. For the purposes of this case study, a total of 11 1:1 interviews with key informants from London Cancer and Queens Hospital were carried out.

Analysis of the interviews resulted in the development of a Context, Mechanisms and Outcomes (CMO) model (figure 11)

The CMO model considers the contexts, mechanisms and outcomes that were apparent in the implementation of the initiative. Each of the key mechanisms is considered in turn within the case study.

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![CMO model](image)

*Figure 11 - CMO model for London Cancer Alliance, Queens Hospital, Romford MDC*

N.B. We do not specifically discuss the second cluster M1-M7 because they are components of the mechanisms discussed Ma-Mf)
D.4.3 Contexts, Mechanisms and Outcomes (CM0)

D.4.3.1 Leadership (Ma)

Context and mechanisms
Initially, London Cancer approached the Head of the Gastroenterology service to see if she would support the ACE project and lead implementation of the MDC pathway. There was a positive response and initial discussions were held with her. Subsequently, she handed over leadership of the project to another consultant colleague.

Characteristics of mechanisms and outcomes
The second consultant responsible for the designated lead responsibilities worked with the London Cancer Quality Manager but it was unclear from the interviews how he liaised with colleagues to develop the project apart from an instance where a particular email lacked clarity. Fellow consultants expressed concerns about the proposed model, which would see a shift from them seeing these patients as part of the on call rota to the patients being slotted into existing outpatient appointment slots.

As the project developed, a third consultant who was an enthusiastic supporter of the pathway became more involved with the leadership of the project and by the time of the second interviews had been designated a joint project lead. It is evident from the interviews that although the project had joint leads, their vision for the project differed as did their perception of the challenges facing the project at the time of the second interviews.

Interpretation
Consistent credible Clinical Leadership is vital for a project to succeed. Where a model of joint leadership is employed it is essential for the leaders to have an clear and shared vision and implementation plan to work to.

D.4.3.2 Connections and communication between professionals (Mb)

Context and mechanisms
There was agreement between the gastroenterologists at Queens Hospital and London Cancer that there were problems with late cancer diagnoses, the high proportion of patients with cancer presenting through A&E and in diagnosing cancers which present with vague or non-specific symptoms. There was also consensus that something new needed to be piloted to try and address this issue. Before initial meetings occurred, Barking, Havering and Redbridge CCG also contacted the London Cancer Quality Manager to say they were interested in supporting the project.
Characteristics of mechanisms and outcomes

Initial discussions between London Cancer and the Lead Clinician at Queens Hospital were positive; however due to the Clinical lead having to deal with some pressing issues relating to accreditation of the endoscopy service, she delegated responsibility for the project to another clinician. The second project lead favoured using the on call rota as a mechanism to deliver the service. There was then a series of meetings between the new lead and London Cancer, with London Cancer believing that was the model to be implemented. However it transpired that not all the other clinicians were on board with this proposed model. The Lead Clinician from London Cancer acted as an intermediary, liaising with all of the consultants and seeking their views on the most appropriate model. It was ultimately decided that the most appropriate model would be to provide the service via outpatients.

From a management perspective there was also a lack of continuity in relation to who was responsible for the project:

“I was asked to participate in this project as it falls within the Upper GI pathway, which is what we manage. I was more involved than I planned due to the sickness absence of the Service Manager in Gastroenterology. The person has now returned to work and is taking a more operational lead . . . . I let the clinicians do that side (agreeing the model and leading the process), and then once they are happy I am more than happy to move forward with things like recruitment to posts . . . “

Speciality Manager

“There has been a lot of restructuring within the speciality and on the admin side which has affected the project. So I think less than two weeks ago XX was told his role was changing, in addition I think he’s, as far as I can remember he probably has at least changed boss twice within six months, that’s a lot.”

Cancer Quality Manager

Lack of continuity and unclear email communications resulted in miscommunication and problems with implementation of the pathway:

“YY sent out an email to colleagues regarding the proposed model and the implications, there was some lack of clarity with it and colleagues weren’t happy to proceed on that basis, so that had to get sorted out.”

Head of Gastroenterology

The project was further disadvantaged due to the fact that key stakeholders, in particular other clinicians expected to deliver the service, were not involved from the outset:

“The people who were supposed to be involved actually weren’t taken on board before the project started. So we were on the back foot to begin with”

Joint Lead Clinician

As the project progressed it became clear that despite initial support from the CCG there were problems with the GPs understanding of the purpose of the MDC and as a result they were making inappropriate referrals:
“So starting at the GP end, the first problem is that the GPs have misunderstood the purpose of the clinic totally, and that comes from the name. If you call it a multidisciplinary clinic, GPs think that’s anything and everything, whether its neurology or cancer or whatever it might be, I’ve had a patient with a neurological problem, because this was multidisciplinary they thought that was the purpose of it”

Joint Lead Clinician

“If there was a flaw, this was incepted from secondary care and not from primary care, this should have been a collaboration from the word go. There should have been a lead in primary care and a lead in secondary care and we should have had meetings and incepted this together and worked out exactly how it’s going to work. Instead what happened was we came up with a project and went to talk to the leads at their cluster meetings, got asked questions. They questioned us. They listened politely and then carried on in their own sweet way”

Joint Lead Clinician

“There were between 20 and 30 referrals so far, so it’s much lower than we would have expected. I think that also comes down to confidence in the community (GPs and communication and buying in to the project. I still don’t feel as if we’ve got our foot on the accelerator at the moment with this, and I think that’s reflected in the GPs. Do I really want to refer this, I don’t know. I don’t know what’s happening . . . .”

Speciality Manager

Interpretation

Everyone interviewed felt that the MDC pathway was a good thing for patients. However there was evidence of poor communication between stakeholders, both in the planning stages of the project and as the project progressed. There was support from the local Clinical Commissioning Group in principle for this initiative but this was not converted to practical help and support.

It was unclear from the interviews as to how much buy in or support came from senior levels and middle management within Queens Hospital. A number of interviewees referred to ‘things being escalated’, and there being board level support. However when probed, interviewees could give no indication as to what progress was made, until final decisions were taken to stop the project. This may have been due to the fact that project leadership changed a number of times and as a result things were communicated inconsistently. With hindsight it may have been helpful to get a board level champion engaged during the planning stages of this project to ensure senior level ownership. A more robust steering group, with membership being identified following a stakeholder mapping exercise, may have also been beneficial. A robust internal and external communication plan also appeared to be missing from this project.
**D.4.3.3 Service/Pathway design (Mc)**

**Context and Mechanisms**

*London Cancer* identified that patients experiencing vague abdominal symptoms often did not have a clear diagnostic pathway. In addition an A&E audit indicated that they had a high number of patients with vague symptoms abdominal symptoms presenting via A&E. As a result of some *London Cancer* stakeholder events the suggestion of developing a Multidisciplinary Diagnostic Centre for patients with vague abdominal symptom emerged.

A proposed pathway was developed by *London Cancer*. Queens Hospital was one of two ACE pilot sites asked to pilot it and adapt it to their needs. A clinical lead who was supportive of the project and receptive to change was identified at Queens Hospital and the team responsible for delivering the project were actively supported by the Quality Manager from London Cancer to develop the pathway in a way which would work for them.

**Characteristics of mechanisms and outcomes**

A pathway with associated referral criteria (described previously in the ACE model section of this case study) and referral forms was developed and went live in September 2015. Patients were referred directly from primary care via the “Choose and Book” system to the MDC.

The role of the MDC Pathway Co-ordinator was seen as crucial to the implementation of the pathway, however due to a short term contract and a combination of other factors the appointee resigned in December 2015:

“She was smart, we got a really smart person who was asking all the right questions, but some of the consultants were confused about her role and she felt dumped on, her manager wasn’t empowered to help her, others were working in silos and then she moved house and felt the commute was too far. That combined with not feeling valued was the final straw”

Cancer Quality Manager

Prior to the MDC Pathway Co-ordinator resigning, concerns about her commitment and competency emerged:

“So she was turning up late for work and forgetting to do things”

Cancer Quality Manager

“The whole key to this project was we had an individual who co-ordinated the patients coming in, made sure investigations were booked and carried out, presented information to the clinicians so they didn’t have to chase things and sort out admin things, but we had an individual who did none of these. So we had patients who weren’t properly booked into clinic. We didn’t know they were coming. The tablet didn’t work, she didn’t make sure it worked. She wasn’t there with the patient. In other words the administration did not work terribly well”

Joint Lead Clinician
Other issues included workload pressure on the Gastroenterologists, a background of organisational change and lack of agreed longer term funding to ensure sustainability. All these were additional factors which affected the successful implementation of the project:

“There was a lack of security for her (MDC Pathway Co-ordinator) role as well . . . . and we had some short term funding from ACE. And then the plan was to make this a long term project with the CCGs. The CCGs wouldn’t give any cash upfront until the project fully expanded, and we couldn’t expand because we weren’t fully confident with the pilot. We didn’t feel we could safely operate that service let alone expand, so it was a vicious circle” Speciality Manager

The project ceased in December, with a plan to restart it in the New Year, however this was not done in a consistent way:

“So there’s been a hiatus since the New Year, a couple of consultants have said they’re not taking part anymore and I’m continuing on a very much ad hoc basis. So the thing has more or less shut down compared to the way it was before.” Joint Lead Clinician

Ultimately the project paused temporarily for three weeks in December 2015/January 2016 and ceased early in March 2016, with a view to trying to re-establish the pathway at some stage in the future.

There are data on 22 patients who were seen via this pathway and there are aspirations to review those patients in order to learn as much as possible prior to trying to re-establish the pathway.

Interpretation

When the first set of interviews was conducted, buy-in from stakeholders was patchy, internal leadership of the project was not evident and there did not appear to be a shared vision regarding the pathway. By the second set of interviews the project was floundering and it was evident that there were issues with referral processes and GPs understanding of the purpose of the service. The pathway co-ordinator may have contributed to this outcome, but equally may have been its victim. Some of these issues may have been avoided had there been a clearly communicated project plan, proactive leadership from the outset and a robust communication plan both internally and externally.

D.4.3.4 Evaluation of capacity: staffing, time and space (Md)

Context and mechanisms

Availability of staff and funding to support them were key contextual issues for Queens Hospital.

The project required Consultant Gastroenterologists or Upper GI Surgeon to see the patients in an outpatient clinic. However the project commenced at a time when Queens Hospital was experiencing a shortage in Gastroenterology capacity.
MDC Pathway Co-ordinator support was key to the successful implementation of the project, unfortunately the initial appointee did not remain in post partly because she did not have a permanent contract due to the short term nature of the funding for the pilot. As a result of her resignation there was a lack of continuity because of the use of temporary staff.

Interviewees reported that there were also problems identifying clinic space to see the patients.

**Characteristics of mechanisms and outcomes**

The shortage of Gastroenterologists led to insufficient capacity to deliver the service, and those Gastroenterologists who were there reassessed their willingness to participate in the project:

“So we have high levels of consultant vacancies in Gastroenterology which means the service is under immense pressure from outpatients, endoscopy, everywhere is under pressure, and when you are under pressure you start to prioritise and you start to focus on the things you think are important, and new projects can often be seen as a distraction from your core business, so that’s been an issue that we’ve got”

Speciality Manager

Diagnostic capacity, including for endoscopy, was not assessed prior the implementation of the project, nor was it really stretched whilst the project was running due to the small numbers of patients which were seen.

Due to a shortage of clinic space, patients were allocated slots in existing clinics, there was no evidence from the interviews that this did not work except when there were issues with the MDC Pathway Co-ordinator (as discussed in Ma) and she forgot to inform Clinicians and clinic nurses that patients had been booked in to a particular clinic.

**Interpretation**

More robust capacity planning in relation to Gastroenterologists capacity would have been beneficial. There was a known shortage of Gastroenterologists prior to the clinic commencing. It is likely that had more patients been seen, there would have also been bottle necks in endoscopy and the existing system would have struggled to cope.

Due to a shortage of key clinician capacity and pressures on those staff remaining it was probably not the most appropriate time to implement a new and complex pathway. Organisations and individuals need to be receptive to change and have the ability to respond proactively to challenges.
D.4.3.5 Questionnaire and technology development (Me)

Context and mechanisms

London Cancer supported the development of an electronic questionnaire by an independent start-up company. The intention was that completing it would aid diagnosis and that the data would be used to help understand presenting symptoms. The plan was for it to be given to all patients when they presented at the first appointment.

Characteristics of mechanisms and outcomes

The questionnaire was uploaded onto a tablet and patients were asked to complete it prior to being seen by the Consultant. However, it seemed to present a variety of problems including patients not liking it, the company made some changes to the format and the actual technology failed:

“It probably affected clinician engagement. I think I was told that since we started this project to where we are now, there’s been at least 20 changes to the software that’s used, or to the programme that’s used, meaning we get a slightly different report each time a change is made . . . . . . . And so I think from a consultants perspective, they’re not too happy with that part of it”

Speciality Manager

“The concept of the tablet, has, to my mind, become a bit of trying to make technology do what is actually a more straight forward process. Actually I found the tablet history, electronic history taking device, practically useless compared with literally a few sentences from me . . . . . . Yeah, but the problem there was that the technology was also flawed. It kept crashing”

Joint Lead Clinician

Interpretation

The challenges in getting the technology to work were frustrating for Queens hospital staff at a time when they were trying to implement the pathway whilst being both under-resourced and not well supported.

The development and use of the questionnaire appears to have been a separate project nested within the ACE project. Although it had been piloted at another site prior to use in the ACE project, it may have been more successful had more development and piloting work been done prior to the implementation of the ACE project.

D.4.3.6 Project review (Mf)

Context and mechanisms

It was intended that the project would be piloted for one year from September 2016. However, the service ceased in December 2015 due to the resignation of the original
MDC Pathway Co-ordinator, it then started again in the New Year, before ceasing again shortly after.

**Characteristics of mechanisms and outcomes**

When the service recommenced it was with fixed term admin staff, there was a lack of understanding about the role, purpose of the pathway and required procedures. Some GPs appeared to have lost confidence in the pathway due to its stop-start nature, while others didn’t understand the purpose of the pathway and, were referring patients who were considered not suitable. In addition, some specialists had also lost interest in the project (for reasons discussed earlier) and ceased to support it. It was therefore decided to stop providing the pathway.

**Interpretation**

Review of the project showed that it was not working for a number of reasons. Having a robust review process can highlight and resolve issues as they arise. In this case, the review mechanisms were able to identify that it was not possible to run the pathway as intended. However it was not possible to deal with these issues as they arose and keep the pathway running.

**D.4.4 Conclusions**

This project provided several important learning points; the need for a clear shared vision, the need for a defined clinical lead, the importance of job planning and for clinicians to have this sort of project work to be included in their job plans, the challenge presented by short term funding for posts and how this can limit the pool of people applying for them, the need for a robust communication plan and good marketing to the right stakeholders, the importance of empowered staff who are able proactively manage problems as they occur and the need to test and refine technology prior to implementation.
Appendix E Vulnerable Groups Cluster Case Studies

Within the vulnerable groups cluster there are a range of projects focusing on increasing screening uptake within vulnerable groups. Two sites were chosen to participate in a realist evaluation: the North East and Cumbria Learning Disability Network and Blackburn with Darwen and East Lancashire CCGs.

Evidence suggests that people with Learning Disabilities (LD) have a poorer uptake of cancer screening opportunities when compared to those without learning disabilities (Osbourne et al, 2012). The reasons for this are often multiple and complex.

The estimated prevalence of people with a Learning Disability in the population is about 2.5%, although GP practice registers tend to record a lower percentage.

Data from the Learning Disability self assessment framework shows that uptake for all cancer screening programmes showed massive inequalities compared to the rest of the population. In addition the Confidential Inquiry into Premature Deaths of People with Learning Difficulties (2013) showed that cancer was a major cause of premature death in this group (similar causation to the general population).

The rationale for addressing the inequalities related to the screening programmes and people with learning disabilities is that:

- People with learning disabilities generally have poorer health and premature mortality.
- Adults with LD are less likely to take part in NHS cancer screening programmes.
- Public awareness campaigns and health promotion messages are not adapted for this group.
- Public services have a legal duty to make reasonable adjustments to support access to such services.

A national event held in 2014 brought together various stakeholder groups and organisations to think about the issue, there was no formal strategic plan developed at that stage but the consensus from those working in the field of learning disabilities is that there is significant scope for the ACE initiatives to inform the national agenda.

Both of the projects selected to participate in the realist evaluation are aiming to ultimately increase screening uptake in the learning disability; however each has a number of secondary aims, including:

- Raising awareness of professionals
- Improving Early diagnosis
- Reducing inequalities
- Reducing premature mortality
- Mainstreaming best practice guidance

The approaches taken differ significantly and will be discussed in more detail within the individual case studies. The North East and Cumbria Learning Disability Network
is taking a strategic approach, leading from the network and aiming for large scale organisational change. Blackburn with Darwen and East Lancashire CCGs are focusing on enabling GP practices to identify their learning disability patients and to promote screening within that group.
E.1 Blackburn with Darwen and East Lancashire Improving uptake of cancer screening for patients with learning disabilities

The following case study describes the implementation of a project to improve uptake of cancer screening for patients with learning disabilities. This qualitative evaluation covers the period to June 2016.

E.1.1 Introduction and Background

The Pennine Lancashire area in East Lancashire includes industrial towns around Blackburn and Burnley as well as more rural areas around the Ribble Valley. The area has two Clinical Commissioning Groups, Blackburn with Darwen and East Lancashire, that serve a population of 540,000 people. The area has 89 GP practices and over 400 GPs and is served by the East Lancashire Hospitals Trust. The hospital and community services are provided by:

- The Royal Blackburn Hospital
- Burnley General Hospital
- Accrington Victoria
- Pendle and Clitheroe Community Hospitals

Blackburn with Darwen is one of the most deprived boroughs in England, covering Blackburn, Darwen and the surrounding countryside. It has a relatively young population with 29% being aged 19 years and under compared with 24% England average. There are high levels of unemployment, and a higher than average rate of receiving incapacity benefit (10% compared with a national average of 6%). There is lower than average life expectancy for men and women compared with the average for England. While life expectancy in the borough is rising, it is not closing the gap with the rest of the county. Smoking rates are among the highest in England at 22.5%, as are the deaths attributable to smoking.

The East Lancashire Clinical Commissioning Group covers five boroughs, four of which contain high levels of deprivation and lower life expectancy than the national average. The population served is around 370,000. The population is aging with increasing numbers of people over 75 years. There is also a higher than national average rate of children and young people. The majority of the population are white British, with around 11% of the population being South Asian. There is also a small Eastern European population within the area. Both the Eastern European and South Asian populations have a younger age structure than the white British Population.

The Pennine Lancashire area has higher morbidity and mortality due to cancer than is found nationally. In 2015, a Local Improvement Scheme (LIS) was introduced. The LIS is defined locally and provides payment to GPs for undertaking certain objectives. The Pennine Lancashire cancer LIS covered a number of areas:

- Reducing premature mortality
- Improving cancer survival, in particular one year survival
- Reduced cancer inequalities within the population
- Improving patient experience across the cancer pathway
The following specific interventions were introduced as part of the LIS in 2015:

- Maintain a practice cancer care team
- Practice Nurse Training on cancer prevention, information and patient reviews
- Review of cancer screening uptake for patients with learning disabilities
- Cancer waiting time targets assurance plans
- Cancer care information for patients with breast cancer
- End of life reviews for cancer

**E.1.1.1 Aims and objectives of the ACE intervention to review cancer screening uptake in patients with a learning disability:**

- Reduce barriers to cancer screening
- Ensure patients with learning disabilities are not inadvertently or erroneously excluded from cancer screening programmes
- Share good practice and advice on supporting patients with learning disabilities to undertake cancer screening
- Train and educate primary health care staff

**E.1.1.2 ACE model**

At the start of the project the area had a Learning Disabilities Directly Enhanced Service (LD DES) to which 85 GP practices were signed up. The LD DES encouraged GPs to undertake a Cardiff assessment health check for patients with learning disabilities. This included recording the outcome of cervical smear test and whether a mammogram had been performed alongside other health indicators. Practices should have a register of patients with learning difficulties and were expected to review this as part of the cancer LIS 2015 and define subgroups that are eligible for cancer screening programmes including:

- Women aged 25 – 64 years for cervical screening
- Women aged 50 to 70 years (extended to 47 – 73 years by 2016) for breast screening
- Men and Women aged 60 – 69 years for bowel screening

The ACE project targeted patients on the Learning Disabilities Register that practices created as part of a previous LD DES. This register would include patients who have an IQ of less than 70 and who were unable to live independently, on average 0.5% of a practice population.

**E.1.1.4 Project Scope**

This was a one year project running from April 2015.

Funding from ACE enabled the Clinical Commissioning Groups to pay the GP practices for participating in the Local Initiative Scheme (LIS).

Midway through the project further CCG financial support funded some administrative and data management activity.
**E.1.1.5 Implementation**

The project was led and supported by a GP Cancer Lead and Commissioning Lead from the Clinical Commissioning Group. Leading and supporting the project was additional activity to their normal roles.

Practices were asked to review data on the proportion of eligible patients with LD who were up to date with cancer screening and compare this to uptake among all eligible patients in the practice. They were asked to review the reasons for non-participation, consider what factors prevented participation in screening and identify measures that could be put in place to improve uptake in each of the screening programmes. These were captured in a structured format (Form 2A). Good practice and resources would be shared across the Clinical Commissioning Group.

As part of the LIS practices were required to review screening data that had been extracted from the MiQuest Database held by NHS England. They were provided with a table detailing the percentage of patients screened for each screening programme. This information was provided as a percentage of the whole practice population and as a percentage of the practice learning disability register population. Practices were also given the average screening uptake for the CCG as a whole, and for the patients with learning disabilities. The number of patients on the learning disability register who had declined or been exempted from screening was also included.

Approximately six months later, and following discussions held at practice locality meetings, practices were asked to reflect on instances where exclusion from screening had been upheld and where it had been changed. They were also asked to consider how patients who had previously declined cancer screening could be supported to participate. These reflections were captured in a structured format (form 2B) and subjected to thematic analysis.

**E.1.2 Methodology**

The qualitative evaluation of the ACE programme draws on the principles of realist evaluation (Pawson and Tilley, 1997) to develop a contextualised account of the way in which change emerges. See section 2.1 for details of realist methodology. For the purposes of this case study, a total of 15 1:1 interviews with key informants were carried out.

Analysis of the interviews resulted in the development of a Context, Mechanisms and Outcomes (CMO) model (figure 12).

The CMO model considers the contexts, mechanisms and outcomes that were apparent in the implementation of the initiative. Each of the key mechanisms is considered in turn within the case study.
E.1.3 Contexts, Mechanisms and Outcomes (CMO)

E.1.3.1 Local Incentive Scheme (Ma)

Context and Mechanisms

The ACE project was an improvement project focusing on reviewing the cancer screening uptake of patients with learning disabilities (previously discussed). The project specifically tried to ensure that patients with learning disabilities were not inadvertently or erroneously excluded from cancer screening programmes:

“I think there is an understanding that people with learning disabilities have a poorer uptake of cancer screening opportunities. And there are lots of reasons for that, it’s quite complex sometimes to actually solve those issues. . . . . . Of course I want to improve that, but I want practices to think about it, and to empower them to change. Because there is a perception that perhaps people are erroneously or vehemently excluded from cancer screening opportunities because they have learning disabilities without making sure all the steps are tried to encourage them to attend”

GP Lead
Characteristics of mechanisms and outcomes

The LIS had a number of activities associated with it, including elements of benchmarking, audit and critical analysis.

The response from practices was good, with 80 out of 89 practices returning form 2A and 68 practices returning form 2B.

There were a number of practices who did not agree with the data presented to them relating to their own practice however this did not appear to stop them participating and often acted as a catalyst for further discussion within the practice:

“So we were quite shocked at the low percentage that was on the front page that we’d received from the CCG, but actually when we drilled down, it wasn’t right, we were much better than that . . . . and the other point is that it’s not just about figures and percentages some people on the learning disability register are just not fit enough for screening, but the whole process has encouraged us to drill down and look at patients on an individual level” Practice Manager

In terms of ineligibility, practices most commonly reported that patients who are thought to be sexually inactive are deemed ineligible for cervical screening as a result. The second most common theme was exclusion after a failure to respond to previous screening invitations. Other commonly reported reasons included informed withholding of consent, parental choice and a decision from a ‘best interest’ conference.

Prior to undertaking any activity to boost screening activity, practices suggested a variety of ways in which screening uptake could be improved. Responses included; using more visual aids such as DVDs and ‘easy read’ materials, including carers in discussions about screening, having a designated practice lead and providing follow up phone calls to patients after a screening invitation has been issued. They suggested a range of reasonable adjustments that could be made to facilitate screening, including timing appointments at the beginning of a clinic to reduce anxiety caused by waiting, giving longer appointments, proactively managing patients who fail to attend, using the annual health checks to promote screening and liaising with the learning disability nurses/health advisors to access additional support.

The completion of form 2B showed that many practices were able to give examples of where the review re-confirmed the original “ineligible” decision. Examples were also given by most practices of patients who as a result of the audit were now viewed as eligible for screening but despite proactive management from the practice still declined to participate.

Following their review of individual patients on the Learning Disability register and the implementation of reasonable adjustments to facilitate screening where appropriate, practices were also asked about factors that helped or hindered this process. Examples were given again of involving carers, using more visual aids such as DVDs and easy read materials, having a designated practice lead and providing follow up phone calls to patients after a screening invitation has been issued.
Flagging patients on practice registers to enable more proactive management was also thought to be useful. Factors that hindered screening participation were centred on a lack of understanding of screening by patients and their carers/relatives, and in some instances practice staff, with communication and education thought to be key factors in addressing this.

In addition to practices sharing their experiences and good practice suggestions the Public Health Screening Lead is currently working with the Project Lead to develop a “Top Tips Guide”

Practices also reported liking this way of working for a number of reasons:

“I think it has flagged up – how can I put it? Some of the areas that weren’t quite as good as they should have been”

Practice Manager

“I think the audit has been useful, it revealed a lady who had previously declined smears and the doctor she likes to see contacted her and was able to explain the procedure using the Easy Help Website (suggested as a resource by the project team) which we weren’t previously aware of so that was good”

Practice Manager

Interpretation

This initiative was essentially a quality improvement initiative (Department of Health, 2008) and although the project team and practices interviewed felt the process to have been beneficial, there is no way of knowing whether this sort of activity will be continued once the incentivisation is no longer there.

One reason cited by practices for the success of the project was the minimal amount of work involved in conducting the audit i.e. most practices have relatively small numbers of patients with learning disabilities and even smaller numbers eligible for the respective cancer screening programmes, the benchmarking data was supplied by the project team and a list of resources was also provided to support the project. Participation may have been less good had practices had to source the data themselves and or had to identify suitable resources to support conversations about screening.

E.1.3.2 Connections and communication between professionals, groups, and other stakeholders (Mb)

Context and Mechanisms

Whilst initial project aspirations were focused on implementing the LIS, the project leads also had other aspirations which involved liaison with staff working in the learning disability arena and collating local and national resources to form a toolkit for practices to use. This sought to address the barrier to screening uptake due to staff and carers attitudes and change the relatively low screening uptake and high mortality rates of cancer in the LD population.
Characteristics of mechanisms and outcomes

GP and Practice Manager meetings, facilitated by the GP Lead, were held at a locality level in order to engage practices with the LIS process and to provide them with their data. These meetings evaluated well and proved to be a useful way of practices providing comment, challenge and suggestions in a safe environment.

In order to maintain communication and keep the project high on practice agendas, the Project Manager regularly emailed practices and was always available to address practice queries and provide support where necessary, there were also updates provided by the leads which were valued by practices:

“I mean obviously we have learning disability updates with XXX and YYY . . . XXX is excellent, he’s the cancer champion and really level headed and gives us lots of ideas and things” Practice Manager

“Yes, if we have any queries YYY is always contactable and approachable and she never makes you feel stupid, but really XXX and YYY have set it up so well we haven’t needed much support” Practice Manager

Initially the project leads met with a range of health care professionals involved in supporting people with learning disabilities, however this didn’t lead to any substantive actions other than an exchange of information.

By the time the second set of interviews were conducted the aspiration of collating local and national resources had been reviewed. Due to the lack of capacity in the project team it was decided that this could no longer be achieved in the time available. However, the Project Manager had assembled a list of resources and circulated it to practices. Contact with learning disability teams in North East and Cumbria allowed learning and materials to be shared so that resources did not need to be developed from scratch.

Interpretation

Peer support is an important factor in the initial engagement with the projects, allowing clinicians to discuss and engage with the information. However, another important factor when communicating with practices is the need for practices to access advice in a timely manner, the fact that the Project Manager was primarily based in the CCG offices appeared to facilitate that accessibility.

In terms of engagement with practices, utilisation of the locality meetings has been an efficient way for the Lead GP to access as many practices as possible thereby making good use of his limited time to devote to the topic. The GP lead was successful in engaging practices because he is well known in the area, is viewed as credible and has a track record of working with practices on similar initiatives.
E.1.3.3 Identification of staffing needs (Mc)

Context and Mechanisms
Both the Project Manager and GP Lead were leading this project in addition to their day roles. As a result some elements of the project had to be reconsidered.

Characteristics of mechanisms and outcomes
Additional funding was successfully sought from ACE to support the data management element of the project. A small amount of additional support was also provided by The Cancer Policy Research Unit to assist in the qualitative analysis of the forms.

The additional support worked well and provided capacity to ensure that the findings from the audit could be analysed and learning could be shared.

Interpretation
Capacity was often cited as an issue and careful planning at the outset of projects can identify the type and amount of support that will be required and where that support will come from.

E.1.3.4 Reviewing learning disabilities register in line with current screening criteria (Md)

Context and Mechanisms
An audit of the LD register and screening uptake was part of the LIS and was undertaken to understand the extent of the problem and the barriers to screening, attitudinal and otherwise, that might exist.

Characteristics of mechanisms and outcomes
The audit was conducted in two stages. Many practices identified patients who were ineligible, often it was due to existing co-morbidities sometimes patients had not been screened due to choice (theirs or parental), some patients had not attended previously and therefore had been removed from the register and another significant group of patients had been deemed ineligible for cervical screening due to lack of sexual activity.

At the 6 month review, many practices provided examples of where they had identified someone previously deemed as ineligible for screening who they now felt was eligible. In addition the majority of practices provided a range of suggestions about how to support these patients and potentially increase screening uptake in this patient group.

Interpretation
Practices interpretation of cervical screening guidelines varied, with some practices deeming that lack of sexual activity indicated that a patient was not eligible for
screening, whereas other practices viewed sexual activity as a risk factor that was considered in conjunction with other factors in deciding whether someone should be offered screening. It was also apparent that in the past, some patients had been removed from the screening programme after failing to attend, and the appropriateness of this action had not been subsequently reviewed.

**E.1.3.5 Individuals leading change (Me)**

**Context and Mechanisms**
Two key individuals led the project, both were viewed as experienced, and credible and were able to lead from the outset rather than having to take time to establish themselves and their credibility. The project also built on previous improvement work and collaborative projects led by them within the area.

**Characteristics of mechanisms and outcomes**
The project was effectively led with all key objectives being addressed, apart from the training and education of primary care staff. There was some reassessment of objectives early on in the project, which resulted in a focus on the elements which the leads thought were attainable, such as the audit, while associated work streams such as the collation of local and national literature and closer work with the learning disability community were dropped.

**Interpretation**
The need to have realistic and achievable objectives in such projects is essential, because too wide a scope can often lead to resources being spread too thinly and a risk of failure.

There is still a need to address some outstanding aspirations, particularly those relating to working with the professionals involved in learning disabilities in order for them to understand the screening agenda and how they can support it.

**E.1.3.6 Service redesign/reasonable adjustments (Mf)**

**Context and Mechanisms**
The LIS audit process was intended to prompt practices to think about what they could do to encourage discussions about screening and how they could adapt their practice systems to facilitate the screening process.

**Characteristics of mechanisms and outcomes**
Practices suggested a range of solutions which might support a person with learning disabilities to consider and where appropriate undertake screening. Suggestions included: Practice Leads, Practice Nurses and/or Clinicians known to the patient contacting them in advance of a screening invitation being issued to discuss the
procedure; giving double appointments to explain then conduct the procedure; liaising with other professional such as learning disability nurses to support the patient; arranging “walk through” visits; providing easy read information and/or DVDs and liaising with family members.

Interpretation

Whilst there were certainly common themes in the suggestions relating to the adjustments that could be made to support people with learning disabilities through the screening process, it is clear that practices differ significantly in the way they approach the management of this particular group of patients. They have different infrastructures and levels of resource and as such, may be best served by being able to select adjustments that would work for them from a range of options.

E.1.4 Discussion

The outcomes specified in the CMO table (figure 12) were evidenced in the following ways:

O1. People with learning disabilities able to make informed decisions – there is evidence from form 2B that patients have been supported to make informed decisions. This doesn’t necessarily mean they have chosen to undergo screening, only that the necessary discussions have taken place.

O2. Increased screening uptake and continuous use of screening- from the 2B returns it appears that some patients are being screened who have previously declined screening or who had not taken a conscious decision either way. However it must be noted that we do not have data to confirm an increased uptake in screening at this stage. It is also too early to determine whether the changes implemented in practices have resulted in a systematic approach to offering screening to people with LD.

O3. Engagement with practices and other services – engagement with practices has been good with 80 practices returning 2A forms and 68 practices returning 2B forms. We have no way of knowing whether practices who did not return the forms attended locality meetings or changed their behaviours in relation to screening and people with learning disabilities.

O4. Understanding barriers to accessing screening services and feelings about screening – practices have started to think about potential barriers to accessing screening from their perspectives but as there was no patient engagement work carried out as part of the project we are unable to say whether the barriers perceived by practices match those perceived by the patients themselves.

O5. Sharing good practice – the suggestions to support informed decision making and potentially increased screening uptake have been shared with practices, also the local Public Health lead has worked with the Project Manager to develop a “top tips” guide to support this agenda. The work has also been shared at the ACE Vulnerable Groups Cluster meetings.
O6. Helping inform further commissioning intentions – a small number of practices identified commissioning issues, particularly in relation to breast screening. The Project Manager is aware of these and considering how best to address them within the commissioning arena.

Whilst the chosen methodology used some of the principles of audit, this project cannot be considered a formal audit as no re-audit was undertaken. In order for his shift in focus to be maintained re-audit would be beneficial. There is evidence to suggest that the process did encourage reflection about both practice level systems and processes and individual patient’s needs.
E.2 North East and Cumbria Learning Disability Network

The following case study describes the processes involved in implementation of a strategic, network-wide approach to improving cancer screening uptake among people with learning disabilities (LD) in the North East and Cumbria over the course of the evaluation from July 2015 to June 2016.

E.2.1 Introduction and background

The project is led by the North East and Cumbria Learning Disability Network working in conjunction with a range of partners including the Cancer Network, NHS England, Public Health England (specifically in relation to screening), local CCGs, Macmillan GPs, Learning Disability providers (NHS, private and voluntary sector) and people with learning disability and their carers.

There is evidence to suggest that people with Learning Disabilities have a poorer uptake of cancer screening opportunities when compared to those without learning disabilities (Osbourne et al, 2012). In 2012/13 across the North East, cervical screening coverage among people with learning disability was 31% compared with a national average of 70% for people without learning disability. The area has one of the highest rates of bowel screening among people with learning disability with 29% having been screened. However this is still lower that the national screening rate of 40% for the general population. As with other screening programmes, breast screening uptake for people with learning disability is lower than among the general population (28% compared with 62.5%)(Glover et al, 2014)

E.2.1.1 Aims and Objectives

To develop a strategic approach to improving the offer and access to NHS Cancer Screening for people with learning disability in the North East and Cumbria.

E.2.1.2 Ace Model

The Learning Disability network applied to the ACE programme for resources to support the delivery of an ambitious programme to establish a new model of working which would increase the uptake of NHS Cancer Screening programmes (breast, bowel and cervical) across the North East and Cumbria. Key elements of this proposal were the appointment of a one year fixed term (seconded) project manager and additional resource to meet project delivery costs.

The project manager role had eight key responsibilities:

- Improving quality and outcomes
- Enabling leadership across the system
- Enabling patient and public involvement
- Promoting equality and reducing inequality
- Partnership and cross boundary working
Leadership for transformational change
Using insight and evidence for improvement
Legacy planning

E.2.1.3 Project Scope
This was initially a year-long project, aiming to influence the national agenda at a strategic level as well as improving services at a local level.

E.2.1.4 Implementation
The infrastructure to support large-scale transformational change already existed in the form of a very well-established and credible LD leadership team that included a clinical lead and programme manager. Previous work by this team has focused on the development of relationships with health, social care, and the third sector; there is evidence from stakeholder events for a shared vision amongst professionals working in the area, to give people with learning disabilities the same opportunities to access NHS screening services as other adults. The leadership team has done a considerable amount of work to test out the appetite for addressing screening inequalities for people with learning disabilities prior to developing a business case for a project manager, including mapping exercises, stakeholder events and reviewing local work. The Learning Disability Network Chair was also the National Clinical Lead for Learning Disability and through his role had worked to build links and influence the national learning disability and cancer agendas. The project manager came into post on the 1st July 2015 for a period of 12 months.

In addition to building on previous work addressing screening inequalities, the project also linked with other North East and Cumbria Learning Disability Network initiatives such as a project to reduce premature mortality in people with a learning disability.

E.2.2 Methodology
The qualitative evaluation of the ACE programme draws on the principles of realist evaluation (Pawson and Tilley, 1997) to develop a contextualised account of the way in which change emerges. See section 2.1 for details of realist methodology. For the purposes of this case study, a total of 18 1:1 interviews with key informants were carried out.

Analysis of the interviews resulted in the development of a Context, Mechanisms and Outcomes (CMO) model (figure 13)
The CMO model considers the contexts, mechanisms and outcomes that were apparent in the implementation of the initiative. Each of the key mechanisms is considered in turn within the case study.
E.2.3 Contexts, Mechanisms and Outcomes (CMO)

This was a wide ranging, ambitious project incorporating a large number of smaller projects. This evaluation identifies the main general themes rather than considering the individual projects.

E.2.3.1 Connections and communications between professionals, groups and other stakeholders (Ma)

Context and Mechanisms

There were separate established Networks for cancer and for learning disabilities in the region with both groups being committed to quality improvement on an individual basis.

There were a number of smaller and informal networks and groups for cancer and learning disabilities already established in the region and the Learning Disability Network was able to make use of these established relationships. However, it also established new groups and networks to drive forward the project.

“The most recently established sub groups of the Network is the primary care liaison nurses who have called it the GAPS network – greater access to primary services”

Network Chair and Clinical Lead
While the Learning Disability and Cancer Networks were both well established, they were not well connected with each other prior to the start of the project. However, connections were developed through the course of the project by the project manager and members of the steering group.

“For me it was all about connections, because you’ve got the learning disability world over here and the cancer world over here, and never the two shall meet. And so I think I was pivotal and helpful in bringing those worlds together.”

Screening coordinator

Connections were also made with cancer and learning disability projects in other geographical areas, such as Cornwall.

“We spent the whole day with the two liaison nurses in Cornwall and learned loads. You know stuff that worked really well for them.”

Network manager

**Characteristics of mechanisms and outcomes**

Connections were made locally with people who could drive the projects forward and involve the right people.

“The next task I had was not only starting to meet the right people who then might actually be able to pass the message, but actually really making sure they were carrying on the message and gathering the right people in”

GP lead

Learning and sharing events for professionals within the area proved successful and were well attended and brought together people from different groups.

“So the event is very much about sharing what we can, physically resources, but also the kind of knowledge and stuff and learning”

Project Manager

“Lots of interdisciplinary, intradisciplinary, geographic, regional and local”

GP lead

The learning from the existing project in Cornwall proved to be important, even though the projects eventually became quite different. A similar model to theirs, using facilitators to support people with learning disabilities, was considered but after discussions within the steering group it was decided that this may not the most effective model for this area and upskilling of current staff would be a more appropriate and sustainable model. Connections with groups in other areas also meant that materials could be shared and did not have to be developed from scratch. For example, material to support uptake of bowel screening that had been developed in Scotland was adapted to make it suitable for the (slightly different) English screening programme.

**Interpretation**

As a defined project in the ACE programme, the team drew upon existing networks and relationships but were also prompted to develop important new ones, and to seek out and learn from the experience of similar initiatives in other areas of the UK.
E.2.3.2 Identification of staffing needs (Mb)

Context and Mechanisms

As a number of projects were developed, a large number of staff from different backgrounds and specialisms were needed to support the projects. Their support was sought in the context of this being a specific project within a high profile national programme of cancer initiatives.

Characteristics of mechanisms and outcomes

To successfully deliver the range of initiatives that were being developed, appropriately trained staff were needed. Engagement with local organisations already providing services provided an effective way to do this in some cases. An example of this was the healthy living events that were run by community learning disability nurses. These were already established and the staff running these events were able to deliver information about screening and cancer as part of the events.

“And we’ve actually been very fortunate, effective, whatever way one likes to twist it, in getting people from key parts of the local sector to actually engage with us”

GP lead

The focus was placed on upskilling and educating current staff in mainstream services. Once the staff currently delivering those services were identified, appropriate resources were provided to increase their skills and confidence. Training came through a variety of formats depending on the needs of the staff, and included educational events, literature and other resources.

“So rather than having a learning specialist, it’s always much better to use the mainstream services”

Network Manager

Interpretation

To run the large number of initiatives embraced by this project and ensure sustainability, work was done to engage the current workforce. To provide an effective service to people with learning disabilities steps were taken to identify and upskill those delivering mainstream services.

E.2.3.3 Project Management (Mc)

Context and Mechanisms

The project manager role was identified as being critical to delivery in advance of the start of the project. A business case was developed and a manager was appointed for one year with funding from the ACE initiative.
The steering group supported the project manager in developing the work programme and the steering group was in turn supported by the project manager.

**Characteristics of mechanisms and outcomes**

There was a clear feeling that the ACE-funded project manager role was vital in the ongoing development of the project and maintaining engagement with the people involved in developing and delivering the work.

“I think without that post we’d have been very slow again, so we’d have lost all the acceleration. And I think we’d have lost some of the audience and the participants in the idea, because we know that happens, don’t we?”

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“And without the project manager I think that would, it would all have hopefully eventually happen just at a very much slower pace”

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The project manager role was initially funded through ACE for one year. However funding was subsequently obtained to extend the post, initially through the Learning Disability Network and then from Macmillan Cancer Support.

The management model for the project evolved organically, rather than following a formal project management model.

**Interpretation**

The role of the project manager ensured that the project moved forward at a faster pace and maintained engagement with all groups involved. While there was a feeling that the project would have happened without the project manager, it is likely that implementation would have been slower and there would have been the risk that impetus would have been lost.

**E.2.3.4 Engaging with people with learning disabilities (Md)**

**Context and Mechanisms**

There are perceived barriers to cancer screening uptake among people with LD and a view that it has a low priority amongst CCGs and Trusts.

Engagement with people with learning disabilities was a priority from the start of the project. People with learning disabilities were involved in developing new materials, chairing meetings, sharing experiences and helping develop the project. Previously people with learning disabilities had not been engaged with service development projects in this region.

**Characteristics of mechanisms and outcomes**

The involvement of people with learning disabilities has been a key feature in the development of the projects and was part of the programme from the outset.
Specific roles were developed where people with learning disabilities could have a role in influencing the work.

“Because we are wanting the people with learning disability to co-produce the work in this project, but we don’t want to do it in a kind of tokenistic way”

Network Manager

“So rather than trying to kind of have people with learning disability on the steering group or in other areas of the project where they can’t necessarily make a direct impact, we’re giving them specific roles within specific projects where there’s a definite impact, there’s a definite need for input”

Project manager

Through educational events for service providers, people with learning disabilities shared their experiences of screening and how services worked for them. As well as sharing experiences, events were chaired by people with learning disabilities. Sharing experiences made professionals reconsider what they could do to help people with learning disabilities make informed choices about screening and act on those choices, and how they could change their services to make them more accessible.

“There were some people with learning disabilities and their families telling stories of how services had worked for them and how their fears had been overcome: some really, really powerful stuff and some huge interest in engagement from primary care”

Network Director

“It was chaired by [GP lead] and a woman with a learning disability. So it sent out a strong message.”

Network Manager

**Interpretation**

Involving people with learning disabilities helped shape the work of this initiative. Sharing stories of people’s experience of screening helped influence professionals’ views and changed thinking about what could be done to help people engage with screening programmes.

People with learning disabilities were involved in several areas of work including the development of literature and in educational events for professionals. The educational events gave the opportunity for service providers to hear from people with learning disabilities about their experiences of using services.

**E.2.3.5 Steering group leading implementation (Me)**

**Context and Mechanisms**

Cancer and Learning Disability networks were already well-established in the region, as well as other third sector organisations and less formal networks. The steering group aimed to be broadly inclusive, while a core steering group was chaired by the GP and consisted of the Learning Disability Network Manager, Project Manager,
Macmillan representative, a representative for Learning Disability Nurses, a local representative from Public Health England and a representative from the cancer network and Inclusion North, a third sector organisation.

“And we want the steering group to be representative of the different parts of the systems, so that we will have somebody from screening at all different levels, and we’ll have people from a learning disability background”

Lead GP

The steering group took a lead in implementing the programmes that will be discussed in the following section.

Characteristics of mechanisms and outcomes

The steering group built itself around the core group, which tried to understand the pathways involved in cancer screening for people with learning disabilities. The steering group then co-opted other professionals to develop and share understanding to ensure they had the right people who could lead and influence the project.

“We had a few meetings where we were kind of trying to understand the cancer screening pathways and the difficulties for people with a learning disability and trying to access those pathways. And once the professionals if you like had that shared understanding, we went on and did the events were we invited both professionals and people with learning disabilities”

Project manager

“I know that if I’ve got the right people at the steering group, and a clear plan of where we’re going and we keep revisiting that plan. So we might say have a meeting a…. we might just need to take stock again and say ‘hang on just a minute, let’s just remember, go back to what it is that we’re trying to do’. And I bring that to the table which seems to work quite well.”

Learning Disability Network Manager

Interpretation

The members of the core steering group represented the different agencies who were involved in the overarching project. They then ensured that the correct people to influence and implement projects were involved when needed. The steering group was chaired by the lead GP who had the advantage of spanning both learning disabilities and cancer networks and was supported by the project manager. While the steering group did bring together cancer and learning disability, it was driven by the learning disability network and so there may have been some missed opportunities to influence the cancer agenda.
E.2.3.6 Local Pilots (Mf)

Context and Mechanisms

The aim of the wider project was to influence the national agenda and become recognised as an example of good practice. As such the challenges influencing national programmes gave the rationale for a series of local pilots, which tested novel approaches, some of which might then be suitable for national implementation.

These included:

- RAIDR (Reporting Analysis and Intelligence, Delivering Results) dashboard
- Bowel Screening flagging
- CQIN (Commissioning for Quality and Innovation) for local breast screening centres

Characteristics of mechanisms and outcomes

RAIDR Dashboard

A dashboard showing up to date data relating to the learning disability population was developed. This allowed practices to see information on their individual patients and CCGs to see practice level data. In turn the Network sought access to CCG level data.

“So we now we have the learning disability RAIDR dashboard and it’s – so at a GP practice you get patient identifiable data on individuals with a learning disability and it also has in there sort of their screening history, whether they’ve been screened or not along with lots of other issues around comorbidity or other conditions they may have, whether they’ve had an annual health check and all that sort of stuff is now on the system....CCGs have an aggregated view of the data”

Project Manager

Bowel screening flagging

In the North East half of the network region, the screening records of patients with learning disabilities were flagged so that the screening hub could work with community learning disability teams to offer support and arrange for accessible material to be sent out with screening invitations.

“So the north eastern side will pilot using the new ability to flag to create a change in the pathway so that they can look at how they can use that to inform GPs that they’ve got somebody coming through with a learning disability and potentially send out easy read material and do it at invite stage.... So we’re going to trial it and they’ll look at that nationally and hopefully take that forward”

Project Manager

CQIN for breast screening centres
The CQIN incentivised good practice by asking breast screening centres to use the information they hold on their recall systems to flag people with LD and to provide appropriate information and support. Evaluation was required as a condition of CQUIN funding. The CQIN was taken up by two screening centres.

“I asked permission from the business people to get the CQIN so that they can be shared around the country and people could see what we’re trying to do”

Screening co-ordinator

Interpretation

While the overarching aim of the programme was to develop a strategic approach to improving access to screening for people with LD, it sought to use smaller local initiatives as demonstrator sites to show how participation in cancer screening could be improved. Three pilots were implemented (a dashboard, breast screening CQIN and bowel screening flagging programmes) and are being evaluated. These have yet to be more widely implemented pending local evaluation.

E.2.4 Conclusions

Some of the outcomes specified in the CMO table (figure 13) were successfully achieved and should be sustainable; for others success and sustainability is less clear:

O1. Dashboard – The dashboard was developed and implemented to give up to date data at a practice, CCG and regional level. Evidence from the interviews suggests that the dashboard is being used by GPs to look at the screening status of people on the learning disability register. The use of the dashboard has not yet been evaluated.

O2. Increased screening uptake – While it is difficult to evidence changes in screening uptake over the short lifespan of the project, work has been done to provide accessible materials to allow informed decision making for people with learning disabilities.

“Some people would argue that actually the outcome would never be about increasing uptake amongst people with learning disabilities ever because it’s about making sure they have informed decisions making”

Public health

“I’m not saying that we’ll definitely be able to evidence that all these extra people have had screening; however, I think if we can acknowledge the fact that we know that the people have been given the information in a manner that they understand and have made a decision made on their understanding”

Learning Disability Nurse

O3. Links between the cancer and learning disability worlds – through the work of the project greater links have been developed between groups and individuals delivering services. This process has been driven by the Learning Disability Network.
O4. Appropriate literature and information given to the right people through IT and flagging systems – The CQIN provided incentives to breast cancer screening centres to provide appropriate support and materials. Changes to the bowel cancer registers to ensure that people with learning disabilities were flagged and appropriate support provided was also implemented successfully.

O5. Sharing good practice – Through contact with other areas, good practices in widening access to screening have been shared. Educational events have been held in all areas of the Network. A region-wide event attended by other regions and national representatives was key in sharing good learning on a wider basis. National links, such as ACE cluster groups and links with other Learning Disability Networks have been used to share learning nationally. Local pilots have been implemented and learning shared; however it is too early to say if these pilots will be implemented on a national level.

O6. Sustainability of work – upskilling of current staff to deliver services increases the likelihood that work can be sustained over the long term. Having a project manager in place moved the project forward at a faster pace and by extending the role it increases the likelihood that the work will be sustained.