Using Cancer Decision Support Tools to support the early diagnosis of cancer

***A**ccelerate, **C**oordinate, **E**valuate (**ACE**) Programme*

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ACE Cancer Decision Support Tools Cluster

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About the ACE Programme

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

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

Executive Summary

This report covers learning from the **ACE Cancer Decision Support Tools Cluster**. This encompassed a series of 3 projects, which sought to understand the use of Cancer Decision Support (CDS) Tools in General Practice. The findings presented here examine the impact, role and utility of these tools for GPs in improving their ability to help to diagnose cancer earlier.

Context

Achieving earlier diagnosis of cancer as a means to improving survival, reducing mortality and improving quality of life is a key challenge identified in Achieving World Class Cancer Outcomes: A strategy for England 2015 – 2020 [1].

Enhancing the ability of GPs to identify those who need a rapid onward referral could play an important role in helping to achieve earlier diagnosis of cancer more consistently. This is a complex task considering the list of symptoms that could suggest a cancer; specifically thinking about the challenge of differentiating concerning vague symptoms from more common (non-cancer) complaints. An investigation of CDS Tools is therefore being carried out with the aim of gaining an understanding of what role they could play in supporting GPs to diagnose cancer earlier.

Cancer Decision Support Tools

CDS Tools are computer based programmes integrated into a GP's usual patient management system. They operate using a range of rigorously researched and developed algorithms that take into account a variety of information about an individual; from age and postcode through to tumour site specific cancer symptoms – resulting in a risk score being generated. It is this score that the GP is able to refer to in helping them to make any decisions around the patient, wherever they might find it to be helpful. There are three main functions of existing CDS Tools:

- **Prompt/alert boxes:** Based on the patient's read-coded details and symptoms recorded in the GP's IT system, a prompt is activated to alert the GP to the potential risk of cancer if the risk score is above a defined threshold.
- **Symptom checker:** If a GP suspects cancer, additional patient symptoms can be entered into the symptom checker template and a risk score will be produced based on relevant read-coded and demographic data. This can be utilised by a GP either following a prompt or by the GP's own choice prior to a prompt. These risk scores can act as a second opinion to support the GP's decision making.
- **Risk Stratification:** Databases held in General Practice containing patient information can be used to produce a collection of risk scores, determining which individuals are at high risk of cancer. These patients can then be contacted and brought in for further investigation where appropriate.

ACE CDS Tool Projects

ACE Projects used the QCancer risk algorithm[2], in most cases integrated within the EMIS IT system.

The main objectives covered by the three ACE projects were:

- To assess what influence CDS Tools have on GPs' decision making around the patient
- To understand how effectively CDS Tools identify individuals who are at high risk of cancer
- To investigate the impact on earlier diagnosis of cancer through linking up with patient outcome and staging data
- To understand how best to spread and improve the uptake and consistent use of CDS Tools in General Practice.

Key Findings

As a support tool, CDS Tools present evidence of being useful to GPs.

The tool was able to help GPs when formulating clinical decisions and also in reinforcing the decisions they had already made. Comments from GPs strongly underline this view; in a survey of GPs involved with project 2, 60% stated that they had used the tool to help in their decision making regarding the onward referral of a patient.

CDS Tools can heighten a GP's awareness of cancer.

CDS Tools worked effectively to bring cancer to the front of GPs' minds during consultations, where they have a variety of potential options to consider. Project 1 displayed that in 82% of cases where the tool had directly influenced the management of a given patient, the GP stated that it had helped them to consider a cancer diagnosis as well as particular, specific investigations. 34% of GPs in project 2 specifically stated that the CDS Tool raised their awareness of a potential cancer diagnosis.

CDS Tools could help with decision making around complex patients.

The support of a CDS Tool in consultations where a patient is presenting with vague but concerning symptoms, and/or has underlying conditions, shows signs of being a key benefit. Project 2 results showed that in 41% of cases where the CDS Tool was used, the patient had at least one underlying condition. CDS Tools may have potential benefit in helping to separate out cancer risk from other possible diagnoses. Additionally, excluding breast cancer diagnoses, this project also reported a number of cancer diagnoses for cancers that are likely to have presented with more vague symptoms, with the CDS Tool attributing a high risk score (above 4.6%) in the majority of these cases.

More research should be done around this, as due to the limited data collected around this in these projects a solid conclusion cannot be drawn. In the second wave of ACE projects, at least one Multidisciplinary Diagnostic Centre will be using a CDS Tool to aid their decision making around complex patients, which will deliver further evidence.

Knowledge of the QCancer risk score can help to legitimise a GP's referral.

A high risk score can help the GP to feel confident in making a fast track referral; with many GPs pointing out that the risk score helped to reinforce their gut feeling. Equally, a low risk score can be shared with the patient in order to reassure them that their risk of cancer is low and that an onward referral is not necessary at that time. This continues to demonstrate a use for CDS Tools as a support to GPs, allowing them to retain their own clinical judgment in decision making.

The association between QCancer risk score and resulting cancer diagnosis is unclear.

Although it was hoped that data from the projects could look into any association between the calculated risk score and resulting cancer diagnoses, this proved to be particularly challenging. Across the projects only limited data linking QCancer risk scores with cancer diagnoses became available for analysis, and no data linking QCancer risk scores with cancer stage. The challenge of this was known at the outset, and the logistics of this would be worth considering for anybody hoping to complete research in this area.

Increased training and promotion of CDS Tools had a positive impact on GP uptake.

Where GPs were well informed on how the CDS Tool they were using worked and what it should help them to do, they were more able and willing to implement it successfully. A survey carried out in parallel with Project 2 demonstrated a clear increase in both uptake and understanding of the CDS Tool, in line with an increased amount of training being reported throughout the year that the project was active.

No observed negative impact on patient experience, following proactive risk stratification.

CDS Tools offer a new dimension to patient consultations; hoping to enhance a GP's ability to diagnose patients effectively – hopefully giving the patient the best experience possible. Project 3, where the intervention provided a new route by which GPs might contact a patient, reported 90% of patients stating that their GP made them feel at ease and that the reason for their appointment was clear.

There is consistency between findings presented by ACE projects and previous literature.

The Unified Theory of Acceptance and Use of Technology model [3] (covered in the introduction of this report) highlights that facilitators to implementation of tools such as these, include factors such as 'trusting the knowledge base', 'reducing threat to decision making' and 'retaining patient relationships' as particularly important. This aligns well with findings from ACE projects, in that GPs were more frequently using a CDS Tool post patient consultation, with a likely reason being so as not to threaten patient relationships. Additionally, a CDS Tool was being used in a supportive capacity, thus it was not threatening or replacing the GP's clinical experience in the decision making process.

Recommendations

- **The use of CDS Tools should be seen as a support to clinical judgment and a way to heighten GP awareness of cancer symptoms.**
- **The utility of CDS Tools with more complex patients, where the GP might ordinarily find it challenging to make a clear referral decision, should be indicated as a main use of the tool for GPs.**
- **Clarity regarding the design and remit of the CDS Tool being used should be focused on as part of the training.**
- **Concerns from GPs around the functionality of CDS Tools should be considered when they are updated. Particularly focusing on making its features as intuitive to use and understand as possible.**
- **CDS Tool effectiveness should be tested with a more defined cohort of patients with vague symptoms and diagnosis and outcomes should be available for analysis.**
- **The effectiveness of CDS Tools at identifying high risk patients across different age groups should be further explored.**

Video Interview

A short video interview was conducted with Dr Tania Anastasiadis, project lead for the Tower Hamlets CDS Tool project. The video details the successes and challenges of the project as seen by Tania, as well as advice she would give to people looking to implement CDS Tools: http://bit.ly/2IqscLW

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Introduction

Background to Cancer Decision Support Tool

Diagnosing cancer at an early stage can vastly improve outcomes[4], and giving General Practitioners (GPs) the ability to more easily identify those who need a rapid onward referral can play an important role in delivering this earlier diagnosis. This is a complex task considering the list of symptoms that could suggest a cancer; specifically thinking about the challenge of differentiating concerning vague symptoms from more common (non-cancer) complaints. There is evidence to suggest that electronic Cancer Decision Support (CDS) Tools can positively impact healthcare providers' performance[1] and so this report aims to assess the utility of CDS Tools in helping GPs to play their role in diagnosing cancer earlier.

Cancer risk algorithms developed by Professor Willie Hamilton (Risk Assessment Tool) and Professor Julia Hippisley-Cox (QCancer) were adapted for use in electronic format on the BMJ Informatica platform, initially for five cancer types: colorectal, lung, oesophago-gastric, pancreatic and ovarian cancers; (Macmillan and partly funded by the Department of Health).

The algorithms were subsequently updated to cover 12 cancer types; now including breast cancer but still not skin cancer. An independent tool has been developed for Malignant Melanoma.
Two ACE projects have been using a CDS tool based on this version of QCancer, with the 3rd project (looking at risk stratification) using a tool with an algorithm based on 5 cancer types.

A CDS Tool assesses the signs and symptoms of patients, as well as other factors such as medical and family history. The tool is integrated into the existing patient management system. Symptoms recorded in the system are cross referenced against indicators for cancers covered by the algorithm. Through this cross checking process the tools produce a risk score for patients; if that risk score is greater than 2% a prompt appears encouraging the GP to review the justification behind the calculation [5].
The risk scores produced by the tool were classified as follows[6]:

Very low: **≤1%**	Medium: **>2 to ≤5%**
Low: **>1 to ≤2%**	High: **>5%**

Updated NICE guidance on referral for suspected cancer (2015) has recommended a threshold for referral of 3% positive predictive value and recommended that CDS Tools should be considered alongside the NICE GP referral guidelines[7].

CDS Tools can also be used for risk stratification across patient records within a practice. Based on patient Read codes (that cover a multitude of factors, including symptoms, previous investigations and family history) those who are deemed to be at high risk can be quickly identified, and action taken as appropriate.

As context for this report, a brief summary of an evaluation of the Macmillan/BMJ Informatica CDS Tool is given below. The results are given as presented in the evaluation report for the Department of Health[6]. This is followed by a review of the literature in this area, to establish what is currently known about the implementation and use of CDS Tools.

Evaluation of the Clinical Decision Support Tool for Cancer Project – July 2014 [6]

GPs from 439 participating practices from across England had access to, and were encouraged to use, a CDS Tool between March and November 2013. A mixed methods evaluation of CDS Tools identified potential factors affecting use, with the main findings presented as follows:

A CDS Tool raised awareness of cancer symptoms and acted as a prompt and cue to users, with GPs reporting that the tool helped them to consider symptoms that may identify a rarer cancer; encouraging a focus on non-red flag symptoms and the consideration of symptom combinations. Improvements in GP education helped the acceptance of a CDS Tool. Through the course of the pilot, a CDS Tool was seen to improve practice in 19% of cases where GPs stated they would not have referred onwards if it had not been for the tool. However, in 21% of cases, the risk stated by the CDS Tool was lower than that perceived by the GP, which may reduce trust in the tool and may be a barrier to use.

There was a concern that a CDS Tool would take the focus away from patients, with mixed views regarding the completion of the symptom checker in the presence of a patient. Some feared that it may detract from the needs of the patient, have the potential for raising anxieties and result in the loss of GP/patient interaction. Some GPs expressed concern that only having a 10-minute consultation was a barrier to use of the symptom checker function, however, patients did mention that they would want to know their potential risk of cancer. Message fatigue and 'prompt overload' was highlighted and could potentially be a barrier to use. Mixed views were received on the usefulness of the risk stratification tool with some seeing its use as burdensome.

The CDS Tool was compatible with all IT systems though some did experience technical problems. It relies on the use of read-coded data and it was suggested that GPs would not adapt their practice and read-coding style to enhance the validity of the tool. There was consensus that the CDS Tool does not suit all GPs' ways of working and not all GPs prefer such tools to other forms of support for earlier cancer identification.

Factors influencing the use of electronic Clinical Decision Support Systems: A narrative review of the literature[3]

Whilst Clinical Decision Support Systems (CDSS) have many benefits to healthcare professionals[4], the provision of such tools does not guarantee uptake[8]. In total, there are just under 9,800 GP practices in the UK[9]. To assist the uptake of a tool, it is important to fully understand the factors influencing its use and adoption and how to change the behaviours of GPs.

The following narrative review aimed to: identify a list of barriers and facilitators to CDSS adoption in GPs; provide a model to help explain the relationship between these factors and identify those of greater influence; and finally, suggest evidence-based interventions that may influence behavioural change in GPs towards adoption of a Clinical Decision Support System.

Behavioural change is a key component to increasing the uptake of evidence in healthcare practice. It has been suggested that multifaceted complex interventions can be effective at changing behaviours[10] but care needs to be taken to ensure that the components of the interventions are well thought-out, based upon the best available evidence and use a relevant, logical and coherent theory.[11] Selection of an appropriate theory is more likely to result in an effective intervention than a purely empirical or pragmatic approach.[11] Selection of a theory helps identify what change is needed and how that change can be achieved.

Seven papers (listed below) were reviewed for the factors affecting use of these tools by GPs.[5] Papers were selected following 2 database searches to identify literature; first on GPs adopting the systems and second to identify theories to influence GPs' practice. The findings are presented in Table 1.

1. Moffat, Ironmonger & Green, 2014.[6]
2. Heselmans et al, 2012.[12]
3. Litvin et al, 2012.[13]
4. Peng Hor et al, 2010.[14]
5. Shibl, Lawley & Debuse, 2013.[15]
6. Simon, Rundell & Shortell, 2007.[16]
7. Varonen, Kortteisto & Kaila, 2008[17]
8. Walter & Lopez, 2008[18]

Table 1 - The facilitators and barriers to use of Clinical Decision Support Systems[3]

	1	2	3	4	5	6	7	8
Facilitators:								
Trust in knowledge base	●			●	●		●	
Agreement with recommendations from the Tool	●		●					
Developed by a trusted source				●	●			
Improved knowledge / professional development	●	●		●	●			
Usefulness in consultation	●	●	●	●	●			●
Assists decision making	●		●				●	
Enables better quality of care	●	●		●				
Patient specific point of care information	●	●						
Facilitates patient discussion			●	●	●			
Embedded patient education			●					
Increased alertness / awareness of symptoms	●	●	●					
Time saver		●	●	●	●			
Ease of use		●		●	●		●	●
External rewards / reporting				●		●		
Involvement in design and development					●			
Ability to make minor modifications to accommodate workflow	●		●				●	
Fit within current workflow		●		●	●		●	
Provision of training			●	●	●		●	
Tool based upon the needs of the practice			●					
Commitment to use the Tool			●					
Acceptance of technology		●						
Openness to use a Tool		●		●				
Barriers:								
Lack of evidence on effectiveness				●				
Poor quality of information / messages		●						
Disagree with recommendations	●		●					
Prompts deemed of limited value			●					
Threat to doctor / patient relationship	●		●		●		●	
Lack of time during consultations	●	●						
Elements of the Tool not deemed useful	●							
Reliability of the Tool							●	
The Tool not intuitive to use			●					
Message fatigue / erroneous information	●	●					●	
Need to adapt personal practice	●						●	
Extra workload	●						●	
Integration with current systems	●			●	●		●	
Computer / network issues			●					
Lack of computers			●					
Lack of an implementation plan				●			●	
Altering the current practice workflow			●					●
Lack of standardised software				●				
Security concerns				●	●			
Loss of reasoning and clinical autonomy				●				●
Resistance to change	●		●				●	
Experience (computer literacy)			●		●			
Lack of financial incentives				●				

The Unified Theory of Acceptance and Use of Technology (UTAUT)

The barriers and facilitators highlighted in this literature review have been mapped against the UTAUT model – a theory which pulls together the elements of 8 different behavioural models. It particularly covers an intervention's: perceived usefulness, perceived ease of use, social influence and the perception that support exists. Many of the barriers and facilitators isolated from this literature search were classifiable against the UTAUT, with a slight adaption to add in features such as 'threat to decision making and patient relationships'.

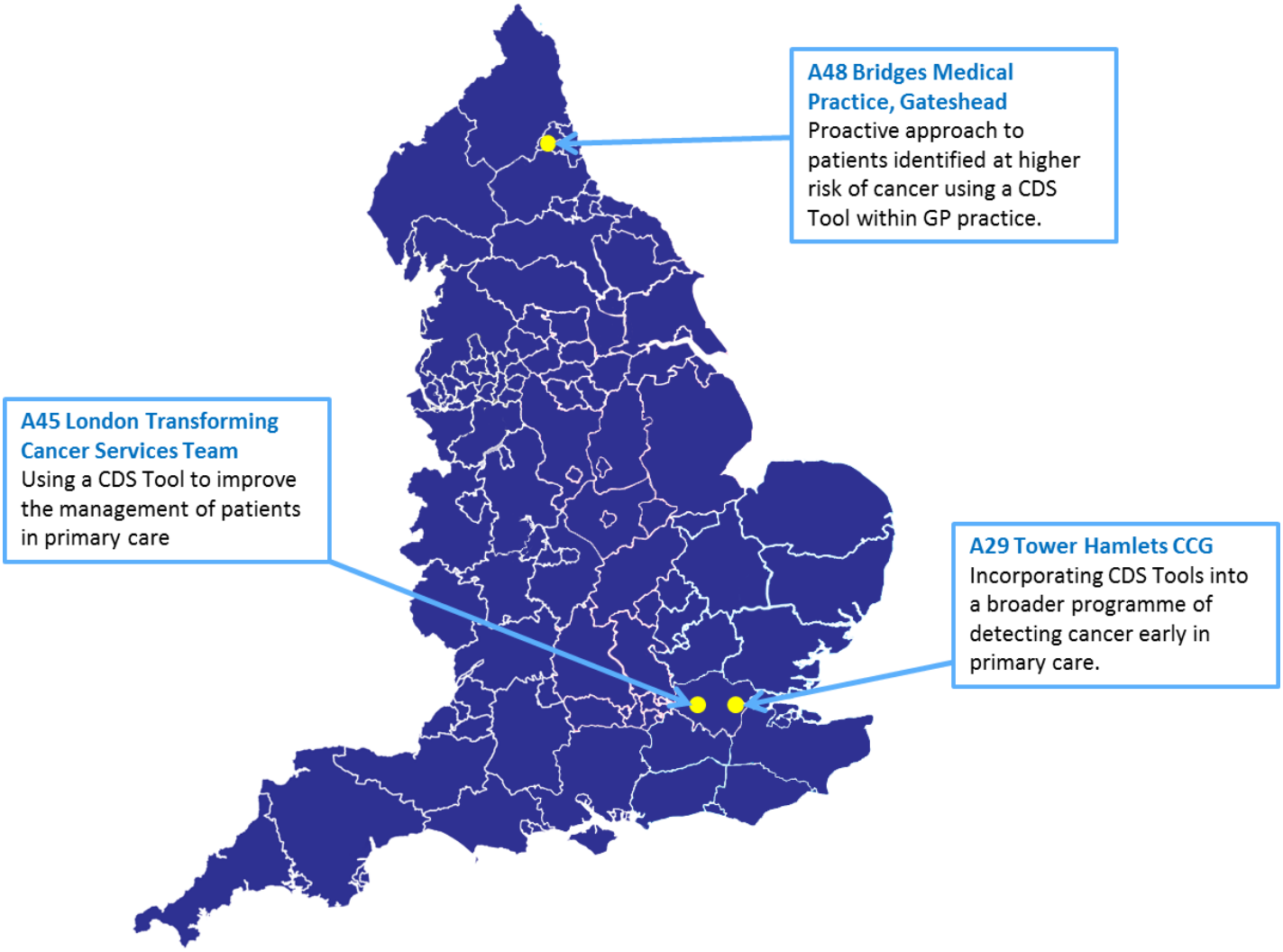
Threat to decision making, performance expectancy, expected effort and facilitating conditions are suggested to have the greatest influence. With the barriers and facilitators from the literature being successfully mapped against this adapted theory, it would seem to be useful to consider it when implementing a CDS Tool. A full analysis of this study can be seen in Appendix B.

Consistencies between these models as well as the previously summarised evaluation of CDS Tools alongside the results of the ACE projects covered here are interesting to note throughout the report.

Projects implementing Cancer Decision Support Tool interventions

This cluster comprised 3 projects, displayed on the map below. This section presents a description of and data from each of the 3 projects. Following this, key findings from across the projects are given along with a series of recommendations around how best to implement CDS Tools following our learning along with additional areas of research that would be interesting to look into, to further build on this work.

Figure 1: A map showing the location of each project implementing a CDS Tool intervention



Project 1 – Using a Cancer Decision Support Tool to improve the management of cancer in primary care across London – Transforming Cancer Services Team

Background

This project, initiated by the Transforming Cancer Services Team (TCST) encompassed GP practices from across London – having invited practices to participate from each of London's CCGs. A Cancer Decision Support Tool integrated into the EMIS GP IT system was utilised.

Project objectives

- To identify higher risk patients; seeking to reduce delay in referral and subsequent diagnosis of cancer.
- To spread the use of and improve uptake of the CDS Tool across London.

Methodology

- A team of existing Cancer Research UK primary care cancer facilitators were mobilised to increase practice awareness of the CDS Tool as well as assisting with making the tool live in EMIS.
- Evidence was generated using an agreed hard copy pro forma. GPs were incentivised at £20 per completed form – each GP was expected to complete a minimum of 10.
- It was hoped the CDS Tool data would be linked with stage at diagnosis and outcome.

Cohort details

A total of 434 forms were received from 15 GP practices across London. 20 records were excluded from the analysis because of duplication or other issues with the completion of the pro forma, leaving 414 records for analysis. Each record corresponded to an individual patient. The data covered a period of 9 months from November 2015 to August 2016.

Age group and sex distribution

Table 1.1 - Number of records by age group and sex

Age group	Male	Female	No sex information	Total	%
<40	6	22		28	7.5
40 to 49	9	36		45	11.4
50 to 59	25	39	1	65	16.5
60 to 69	42	38		80	20.3
70 to 79	57	52		109	27.6
80 to 89	27	40		67	17.0
Sub total	**166**	**227**	**1**	**394**	**100**
No age information	8	11	1	20	-
Total	**174**	**238**	**2**	**414**	**-**

Table 1.1, above, shows the number of cases for which the pro forma was completed, by age and sex. The male patients (median age 70) were typically older than the female patients (median age 65).

For the purpose of subsequent analyses we collapsed the age groups to < 50, 50 to 69, 70+ and no information.

Deprivation

The Townsend score, a measure of deprivation derived from four census tables and based on the place of residence of the patient, was available for 399 out of 414 records.

Positive Townsend scores are indicative of areas with high material deprivation, while negative scores reflect relative affluence. The scores ranged from -5.58 to 22.5 with 77% of records showing a score with a positive value.

QCancer risk score distribution

Table 1.2 - Number and proportion of cumulative QCancer risk score for the overall cohort and tumour specific QCancer risk scores for colorectal, lung and breast cancer

QCancer risk score (%)	Cumulative QCancer risk score		Colorectal		Lung		Breast*	
	N	%	N	%	N	%	N	%
<3	135	32.6	358	89.1	360	89.6	214	92.2
≥3	279	67.4	44	10.9	42	10.4	18	7.7
No information* *	-	-	12	-	12	-	6	0.1
Total	**414**	**-**	**414**	**-**	**414**	**-**	**238**	**-**
Median score	5.50		0.38		0.31		0.46	

** Females only.*

*** In some cases, individual tumour scores were not recorded and only a cumulative score is known.*

Table 1.2 shows the number of records created, by QCancer risk score. The split of cumulative risk scores between <3 and ≥3 was markedly different to that of the tumour specific scores for each of the three tumour types. The tumour site specific QCancer risk scores each showed around 90% of the cohort had less than 3% risk, while 32.6% of the cohort had less than 3% risk for the cumulative score.

Figure 1.1 - QCancer risk score by age group and sex

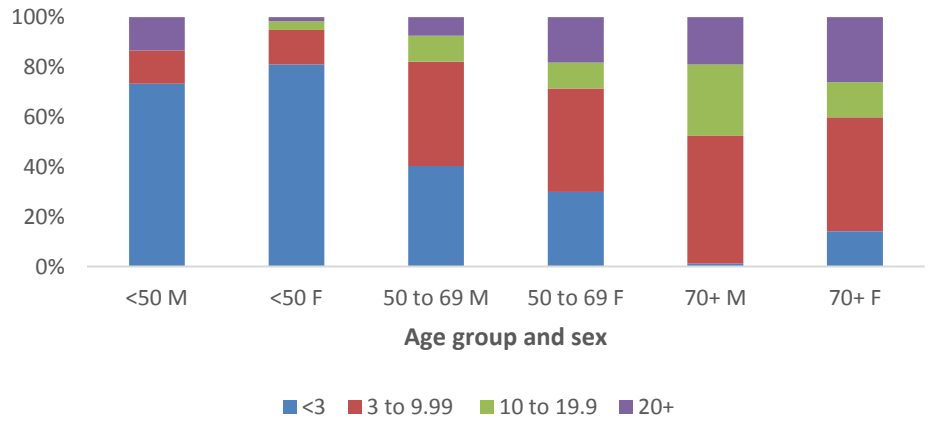


Figure 1.1 shows QCancer risk score by age and sex. The older age groups show higher modal QCancer risk scores in both sexes – consistent with the incidence of common cancers increasing with age. Over the age of 70, very few people recorded a risk score of less than 3 (particularly males).

Decisions taken as a result of the consultation

At least one decision was recorded for 397 of the 414 patients. GPs were able to record more than one decision for each patient - 117/397 records contained more than 1 decision made as a result of the consultation. Results are shown in Table 1.3

Table 1.3 - Number of decisions reported

Decision made	N	%
Fast Track	210	52.9
Diagnostic Tests	131	33.0
Safety Netting	69	17.4
Reassured	45	11.3
Referral for further care	42	10.6
Active Surveillance/ Review Appointment	34	8.6
No information	17	-
Total records with at least one decision	*397*	

Diagnostic tests ordered

34% (141/414) of records reported at least one diagnostic test being ordered as a result of the consultation. The total number of tests carried out was 176. The distribution of diagnostic tests ordered is given in Table 1.4.

Table 1.4 - Number of diagnostic tests reported

Diagnostic test	N
Blood Test	92
Chest x-ray referral	35
Ultrasound Scan referral	32
Colonoscopy referral	9
Endoscopy referral	6
Flexi sigmoidoscopy referral	2

Use of the prompt by GPs

Out of 316 records available for analsyis, a large majority (75%) of GPs chose to use the symptom checker prompted by their own clinical judgment while 25% (79/316) used the symptom checker when prompted by the CDS Tool.

Of the 10 GP practices that provided at least 10 forms, GPs at 7 practices chose to use the symptom checker as a result of clinical judgment in the majority of cases. There were no practices at which the majority of uses of the symptom checker had been due to a prompt from the CDS Tool.

Impact on patient management

Table 1.5 shows the influence of the symptom checker on the management of patients, both during and after the consultation.

Table 1.5 - Use of the symptom checker and influence on the management

	Use of symptom checker					
	During consultation		After consultation		No information	Total
Influence on management	**N**	**%**	**N**	**%**	**N**	**N**
Yes	40	34	19	9.5	14	73
No	77	66	182	90.5	76	335
Subtotal	117	100	201	100	90	408
No information	-	-	1	0	5	6
Total	**117**	**-**	**202**	**-**	**95**	**414**

In 37% (117/319) of cases where information was provided, GPs reported using the symptom checker during the patient consultation. In 34% of these cases it was stated that the symptom checker specifically influenced their management of a given patient. When the tool was used after the consultation, this decreased to 9.5%. Further, 68% (40/59) of the cases in which the CDS Tool directly influenced a GP's management of their patient came as a result of having used it during the consultation.

Table 1.6 - Knowledge of QCancer risk score and influence on the management

	QCancer risk score (%)								
	<3		3 to 9.99		10 to 19.9		20+		Total
Influence on management	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**
Yes	15	11.4	35	22.3	6	10.5	17	27	73
No	117	88.6	122	77.7	50	87.7	46	73	335
Subtotal	132	100	157	100	56	100	63	100	408
No information	3	-	2	-	1	-	-	-	6
Total	135	-	159	-	57	-	63	-	414

Table 1.6 shows the influence that the tool had on GPs' management of patients, broken down by the cumulative score. The greatest influence occurred in cases where the score was above 20, closely followed by patients whose score was between 3 and 9.9.

When considering the 73 returned pro forma that reported the QCancer risk score had influenced their management of a patient, 60 added additional comments outlining that knowledge of the risk score helped them to consider further referrals as well as additional and more specific investigations. In some cases this was reinforcing an initial gut feeling; helping to legitimise their referral decision.

Patient Consultation

Table 1.7 - Age group of patient and disclosure of QCancer risk score

Age group	QCancer risk score			
	Not shared with patient	Shared with patient	No information	Total
<50	60	12	1	73
50 to 69	98	44	3	145
70 +	146	28	2	176
No information	14	5	1	20
Total	**318**	**89**	**7**	**414**

Table 1.7 shows that 22% (89/407) of the records reported that the QCancer risk score was shared with the patient. GPs shared the QCancer risk score with those aged 50-69 most frequently, doing so in 31% (44/142) of cases. Being able to share the QCancer risk score with the patient can work to either help a patient to understand the importance of a referral or to reassure them of the low risk and that a referral is not needed at that time.

Additional qualitative comments

A total of 150 comments were added to the forms from GPs as part of the project. The majority of comments were not specific to the use of the symptom checker, and mainly referred to the patient presentation. In a few cases it appeared that the QCancer risk scores were not interperted correctly. For example, a cancer diagnosis following a risk score above 3% was a surprise for one GP. In another case the symptom checker led to a discrespancy between the QCancer risk score given and the red flag symptoms that were being presented.

Other issues highlighted by GPs included that the CDS Tool did not take into account previous tests done or medical history. This is of particular interest as the premise of the algorithm underpinning and driving the CDS Tool is based on GP coding and patient notes. An important factor to consider here is how consistently previous tests and medical history have been coded on the system.
The main design issue brought up focused on the lack of symptoms for skin lesions as well as the failure of the symptom checker to pick up on breast pain.

Discussion

The data analysis was based on responses from GPs who participated in the project and submitted paper copies of the pro forma. Despite incentives being in place the project team struggled to recruit as many GPs as they had initially been aiming for.

There are some limitations to the data and to this approach so it is important to be cautious when interpreting the overall findings. There were issues with some of the returned pro forma, particularly as limited responses were captured for some questions and answers for some questions were ambiguous.

The majority of analysed cases reported a QCancer risk score of less than 10%, with 32.6% of cases recording a risk score of less than 3%. The built in prompt encouraging GPs to use the symptom checker is triggered by a QCancer risk score of 2% or above. Overall, 52.9% of cases were referred as a fast track referral.

Unfortunately the staging and outcome data did not become available for analysis and it was therefore not possible to look for any association between QCancer risk score, referral decisions and patient outcomes.

Focusing on whether or not using the CDS Tool influenced GPs decision making, this project provided interesting data. In 34% of cases where the CDS Tool was used during the patient consultation, GPs stated that it did influence the management of their patient. However, in the majority of cases, the tool was being used after the patient consultation. This was perhaps due to the limited time available within a consultation - the symptom checker could be seen to be a time consuming addition. When the GP did use the CDS Tool during the consultation, it was more likely that it influenced their management of the patient. This could be because GPs were choosing to use the CDS Tool during the consultation for more complex cases, where they felt the symptom checker could give a useful second opinion, and aid their decision making. After the consultation they were more likely using the tool as a way to reflect on and confirm referral decisions that they felt more confident making without the support of the tool.

A number of comments from GPs strongly underlined the view that the CDS Tool helped to formulate their clinical decisions and also to reinforce their initial clinical judgment regarding a course of action for the patient. The CDS Tool was being used as a support, helping GPs to reflect on their own clinical judgment; it is unclear, however, if knowledge of the QCancer risk score specifically influenced GPs decision making.

There were comments relating to the limitations of the CDS Tool regarding some presenting symptoms for skin and breast cancer however the tool was not designed to be used for skin cancer and therefore these comments highlight an issue around CDS Tool training. In terms of breast cancer symptoms there were reports that they did not get recognised by the tool.

It is important that the tool be as intuitive to use as possible so that only limited training be required; it should be clear for which cancers and symptoms the tool is appropriate. Particularly looking at breast cancer, it is likely that these patients present with clearer symptoms making the CDS Tool less necessary.

To conclude, there were mixed comments on the CDS Tool with some GPs highlighting its limitations, however, it was encouraging that the data suggested the majority of GPs felt it did support them in making their clinical judgments. Whilst there is no patient outcome data to demonstrate whether the Tool supported an earlier patient diagnosis, these findings do help us to understand how new technology can support GPs and build on the emerging evidence base, alongside the other projects presented in this report.

Project 2 – Measuring the impact of a Cancer Decision Support Tool as part of a programme for the early detection of cancer in Tower Hamlets

Background
The project was part of a programme of service improvement on early diagnosis and the recording of data followed a year of promotion for the adoption of a Cancer Decision Support (CDS) Tool within the EMIS GP IT system.

Project objectives
The overall aim was to measure the impact that the CDS Tool had on GP behaviour and to assess the affect it had on resultant stage of cancer diagnoses.

Methodology:

- GPs were asked to use the CDS Tool in consultations with patients who present with cancer symptoms or may be at risk of cancer.
- GPs completed a clinical effectiveness group (CEG) template to record CDS Tool use and action taken (or not) as a result of those consultations.
- The QCancer risk score calculation was integrated into EMIS, and captured any clinical action alongside patient information. These data were extracted from EMIS for analysis.
- Once the staging data became available, it was hoped this could be linked back to any patients diagnosed with cancer.

GPs were incentivised to complete the integrated EMIS templates at a cost of £20 per template.

Quantitative data analysis:

Cohort details
A total of 582 patient records were supplied for analysis, of which 15 were not included due to the absence of QCancer risk score data or multiple consultation dates for the same case. This left 567 patient consultations. The dataset comprised all registered patients across Tower Hamlets for whom a QCancer risk score had been recorded, covering the period from 1 April 2015 to 31 March 2016.

Age group by sex distribution

Table 2.1 - Age group by sex distribution

Age Group	Male	Female	Total	%
<40	30	41	71	12.5
40 to 49	44	45	89	16
50 to 59	58	71	129	23
60 to 69	44	85	129	23
70 to 79	27	44	71	13
80+	41	37	78	14
Total	**244**	**323**	**567**	**100**

Table 2.1 shows the age and sex of the patients for whom QCancer risk scores were recorded. Of those, 43% were male. The CDS Tool was mainly used with those of middle to late age, with 72% being aged 50 or over.

The age range for which the CDS Tool was used varied substantially across the practice networks. This may reflect the practice population to some extent, but it is also likely to be influenced by individual GP decisions to use the tool. Overall 7 out of 8 practice networks applied the tool predominantly to patients between 50 and 69. In one network the tool was most frequently used for patients less than 50 years of age.

Ethnicity

Table 2.2 shows the ethnicity of the cohort, compared with the census population in Tower Hamlets.

Table 2.2 - Broad ethnicity by sex

Broad ethnic group	Data collected as part of the project				Tower Hamlets (2011 census)	
	N			%	%	%
	Male	Female	Total	Total	Unadjusted	Age-weighted*
Asian / Asian British – Bangladeshi	92	124	216	39.2	32.0	21.9
White British	90	112	202	36.7	31.2	49.6
Black/ Black British	17	28	45	8.2	7.3	8.1
White Other (incl. Irish)	19	23	42	7.6	14.0	10.8
Asian / Asian British – Other (incl. Chinese)	11	10	21	3.8	9.1	6.0
Other / Mixed	9	16	25	4.5	6.4	3.7
All (known ethnicity)	**238**	**313**	**551**	**100.0**	**100.0**	**100.0**
Unknown	6	10	16			
All (including unknown ethnicity)	**244**	**323**	**567**			

***** *Ethnic distribution of population of Tower Hamlets, weighted by age distribution of data collected (10-year age groups)*

The ethnic classifications were configured into broad groups due to small numbers being present in some more specific groups. The largest category was Bangladeshi, comprising 39% of patients with known ethnicity. White British were the next largest group, comprising 37% (201/551) of patients.

In comparison to the population of Tower Hamlets as a whole (as per the 2011 census), the Bangladeshi and White British groups were each over-represented by around 20%. Taking into account the age weighted ethnic breakdown of Tower Hamlets (in 10-year age groups) the number of consultations carried out on members of the Bangladeshi community was around 80% higher than would have been expected; conversely, the White British group were under-represented by around 25%.

Previous cancers

There was a recording of a previous cancer diagnosis, spread across tumour sites, for 35 patients (6%). It is not clear how complete the recording of a prior cancer is and the number of pre-existing cancer diagnoses recorded is likely to be underestimated due to a lack of complete data.

Co morbidity

The co-morbidities of patients were recorded under seven categories. Table 2.3 shows the numbers of patients by number of co-morbidities recorded for them. Table 2.4 shows the co-morbidities recorded by category. 41% of patients with which the CDS Tool was used had one or more co-morbidities, as recorded by the GP.

Table 2.3 - Number of reported co-morbidities per record

Number of co-morbidities reported within the same record	N
0	333
1	166
2	43
3	18
4	5
5	2
Total	**567**

The most frequently reported co-morbidity was diabetes, recorded in 149 cases. This relatively high rate reflects that such patients will have a high frequency of visits to primary care. This probably also accounts for the large proportion of patients with one or more co-morbidity.

Table 2.4 - Co-morbidities by category

Co-morbidity types	N
Diabetes mellitus	149
Chronic obstructive pulmonary disease	65
Ischaemic heart disease	55
Stroke / transient ischaemic attack	21
Atrial fibrillation	19
Heart failure	14
Peripheral arterial disease	13

QCancer Risk Score

All records retained for analysis had information on the QCancer risk score, however, the majority (368/567) did not have individual tumour site specific QCancer risk scores recorded (as shown in Table 2.5). The incompleteness of these data made it very challenging to evaluate it any further, thus comments from here on are based on just the cumulative risk score recorded for each patient.

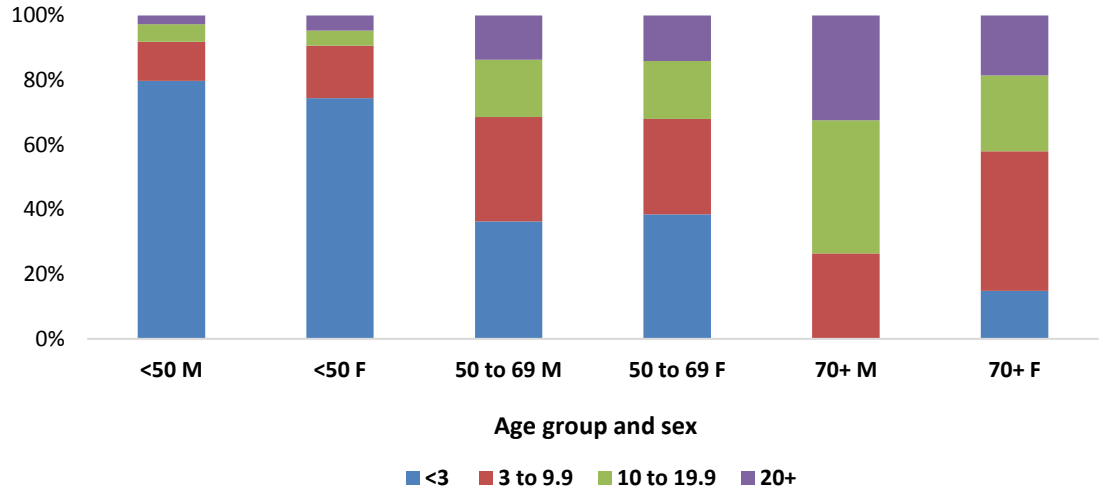
Table 2.5 - Number and proportion of cumulative QCancer risk score for the overall cohort and tumour specific QCancer risk scores for colorectal, lung and breast cancer

QCancer risk score (%)	Cumulative risk		Colorectal		Lung		Breast *	
	N	%	N	%	N	%	N	%
<3	232	40.9	86	65.6	58	74.4	35	100
≥3	335	59	45	34.3	20	25.6	-	0
Sub total	567	100	131	100	78	100	35	100
No information	-	-	436	-	489	-	288	-
Total	567	-	567	-	567		323	-
Median	**4.05**		**1.64**		**0.93**		**0.31**	

**Females only*

QCancer risk scores are shown by age and sex in Figure 2.1. Consistent with the incidence of common cancers increasing with age, the older age groups show higher modal QCancer risk scores in both sexes. It is noteworthy that no males aged 70+ had a QCancer risk score less than 3. In the younger age groups, the distributions of QCancer risk scores were similar between males and females

Figure 2.1 - QCancer score risk by age group and sex



Diagnostic activity

The information on diagnostic imaging procedures was incomplete with only 199 records reporting referral to diagnostic imaging procedures. Only the first test carried out was recorded. Ultrasound was the most commonly reported procedure (74/199 patients), followed by X-ray (66/199). These data are summarised in Table 2.6.

Table 2.6 - QCancer risk score by diagnostic imaging procedures

Imaging Procedure	N
Ultrasound Investigation	74
X-ray	66
Endoscopy	32
MRI	19
Sigmoidoscopy	8
No imaging reported	368
Total	**567**

Patient management decisions

Patient management decision by QCancer risk score

Patient management decisions (subsequent to the use of the CDS Tool) were recorded for 362 patients (64%). Of these, 122 (34%) were put on a fast track cancer referral pathway, 113 (31%) were referred for further care, 78 (21.5%) were put under active surveillance, and in 49 cases (13.5%) GPs reassured the patient they did not need a referral at that time.

Fig 2.2 – Proportion of patient management decisions by QCancer risk score

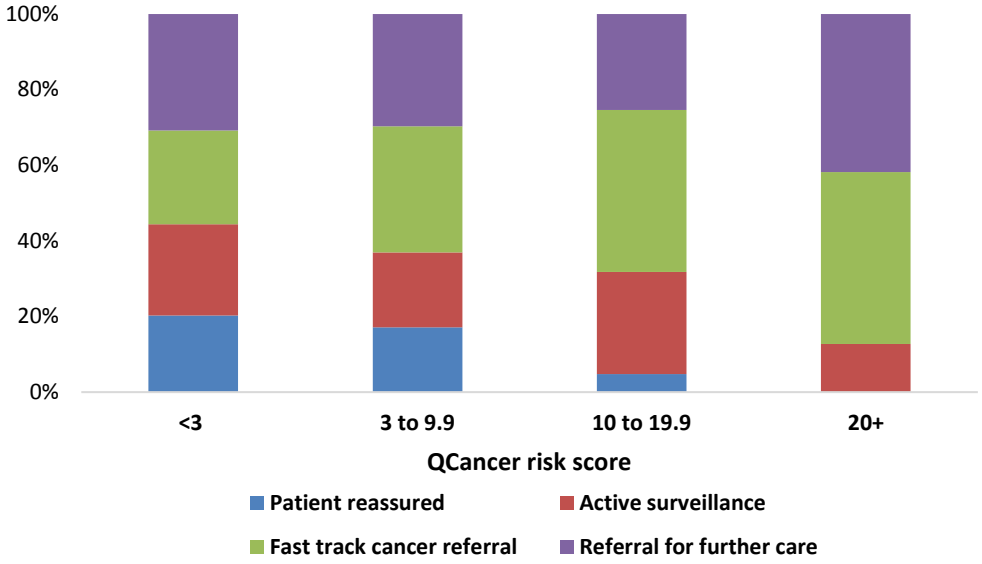


Figure 2.2 shows that the proportion of patients where the GP reassured the patient that their risk of cancer was low decreased (20.3% to 0%) as the QCancer risk score increased; thus GPs took positive action in all cases where a patient's risk score was above 20. The proportion of overall referrals (fast track and referral for further care) increased in line with the QCancer risk score. As with the imaging procedures (Table 2.6), referral data were understood to be incomplete, and therefore caution should be exercised in attempting to draw conclusions.

Looking across all categories, the group with the highest proportion of GPs electing to reassure patients of their low risk was those with a risk score of <3. However, even in this group, there were a number of patients for whom the GP did take positive referral or surveillance action.

Figure 2.3 - Proportion of patient management decisions by age group

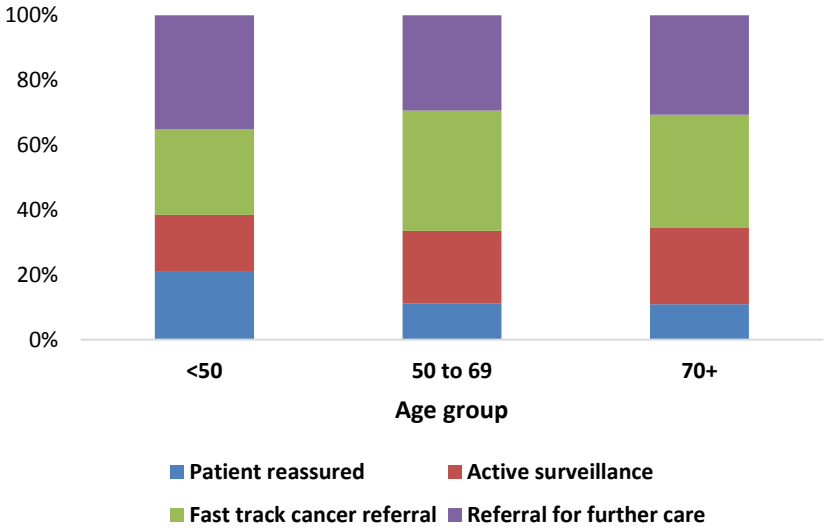


Figure 2.3 shows the proportion of patients being reassured by the GP were highest (21%) in the <50 age group and down to 11.2% and 11% in the 50 to 69 and 70+ age groups respectively. The percentage of patients who were fast tracked was higher in the 50 to 69 age group (37%) and the 70+ age group (35%). The proportion of active surveillance increased with age (18% to 24%).

Cancer diagnoses

Table 2.7 - QCancer risk score and resultant diagnoses

QCancer risk score (%)	Total	Cancer diagnosis (N)		
		No	Yes	% Cancer diagnosis
<3	232	224	8	3.4
≥3	335	327	8	2.4
Total	**567**	**551**	**16**	**2.8**

Table 2.7 shows that 16 patients) received a cancer diagnosis. In three of these cases a cancer of similar origin had previously been diagnosed The action taken as a result following consultation for these 3 cases is still relevant, so they were included in the analysis.

The most common tumour site was breast followed by gynaecological, haematological, lung, urological, head and neck, Lower Gastro Intestinal (GI) and Upper GI tract cancers. Caution should be applied when interpreting the data regarding cancer diagnoses due to the known under reporting of these data in the EMIS IT system.

The cumulative QCancer risk score for those diagnosed with a cancer ranged between 0.34 and 71.42, with a median value of 3.55. All QCancer risk scores known for diagnosed breast cancers were less than 3%, but in all cases were referred onward by the GP following consultation. Due to the incomplete recording of scores, and the small number of cancers diagnosed, it was not considered appropriate to carry out any further analysis on the individual component scores.

Table 2.8 - Outcome by patient management decision

Patient management decision	Total	Cancer diagnoses
Patient reassured	48	0
Active surveillance	78	3
Fast track cancer referral	122	6
Referral for further care	114	5
No information	205	2
Total	**567**	**16**

Tables 2.8 shows that in all cases where the CDS Tool was used and a cancer diagnosis was later made, the GP took positive action - actively surveying the patient as a minimum. In no recorded cases did the GP choose to reassure a patient that their risk was low, only for them to turn up in the system later and receive a cancer diagnosis.

Discussion

The analysis of the data was informative but had limitations due to the lack of some key data items such as imaging data and tumour specific QCancer risk scores. In addition, the EMIS IT system used for the analysis is known to slightly underreport cancer diagnosis.

It is likely that the use of the tool was influenced by the nature of patients presenting. 41% of patients had one or more co-morbidities, the commonest being Type 2 diabetes mellitus (26% of cases). This illustrates the potential use of the tool in aiding a GP's decision making when presented with complex cases and in particular the recognition and referral of some cancers with co-morbidities masking disease; for example, Chronic Obstructive Pulmonary Disease (COPD) (present in 11% of cases) which may mask lung cancer. Additional comorbidities may have been present in even more patients, but not recorded in this data extraction – particularly notable is that no data on patients presenting with dementia was captured.

There was an association between patient management decisions taken by the GP and QCancer risk score, with the proportion of GPs taking the action of reassuring patients decreasing as the QCancer risk score increased and the converse for patients being referred for a 'fast track referral'. The definition and recording of 'patient reassured' and 'active surveillance' used in the template does lead to some queries regarding the GP's interpretation of what each of these items meant, and so there is potential overlap here.

The proportion of patients referred for further care was slightly higher in the under 50s and might be explained by a higher uncertainty due to the rarer occurrence of cancer in younger people.

The majority of cancers diagnosed among this cohort of patients came as a result of a fast track referral or a referral for further tests, rather than the patient being 'reassured' at the initial consultation and then turning up in the system at a later date. This suggests that, although the association between cancer diagnosis and QCancer risk score was not clear, it may still have been effective in bringing cancer to the front of the GP's mind. The GP then retained the decision making authority, having considered the QCancer risk score alongside the patient in front of them.

A quarter of the cancers diagnosed were breast cancer. Breast cancer patients tend to present with clearer symptoms than other cancer types and it is likely, therefore, that GP did not require the support of the tool in their decision making. This works to explain the surprising "low" risk scores recorded for patients later diagnosed with breast cancer, as GPs were probably not fully utilising the tool.

The literature highlights that in many cancers older males present late and it is interesting to note that no QCancer risk score of less than 3% were reported for males over 70 year old. In comparison a large proportion of QCancer risk scores below 3% were recorded in younger patients, both males and females, as expected in line with occurrence of cancer in the overall population.

Despite the small amount of outcome data available and some missing data, there are indications that the majority of patients diagnosed with cancer who were consulted by a GP using the CDS Tool were referred appropriately for further care.

Qualitative Results:

GP Survey in Tower Hamlets

This survey was carried out independently of the previously discussed quantitative data, but was aimed at GPs from the same area who were involved with the project.

An initial survey was circulated in July 2015 and a follow-up survey was distributed during July 2016.

The majority of GPs surveyed use the CDS Tool integrated within EMIS, which uses the QCancer risk algorithm.

Initial Survey

From the GP survey conducted in 2015 there were 21 responses. 85% of GPs who responded had access to a CDS Tool, with a small minority noting that although they had access to the Tool, they had never used it.

"It is one more thing to think about in a busy GP consultation, when we are used to diagnosing on history, examination etc."
GP 1

It was noted that the majority of GPs had not had training on how to use a CDS Tool. Those that had, had learned via colleagues and the CCG cancer lead. On the subject of training 50% of GPs stated a preference for a cancer education meeting in their locality compared with 35% who would rather have a training session within their own practice.

16% of GPs who used the tool found that it raised their awareness of cancer, however, the majority had either not used the tool or had not found it useful. A couple had found that the tool's recommendation matched their initial findings, with 30% of responders highlighting they had used the CDS Tool to help in their decision making on whether a patient needed further investigation.

"Useful, when I was indecisive about where I was justified in a 2WW referral"
GP 2

"Yes, especially when I suspected cancer due to X symptoms and was not sure where it is, or how to investigate further"
GP 3

Follow-up Survey

From the GP survey conducted in 2016 there were 29 GP responses. 93% of the GPs that responded to the survey had access to a CDS Tool.

Responses indicated that GP training around the use of CDS Tools had increased since the evaluation in July 2015. 85% of the GPs who responded had received some form of CDS training compared to a small number in 2015. Still, the type of training varied, and at times appeared to be ad-hoc rather than formal training, with the majority of GPs not selecting one of the categories, but described informal training at practice or CCG level, local meetings, Protected Learning Time sessions or discussions with the Cancer Lead.

34% of GPs reported that the tool had raised their awareness of the possibility of a cancer diagnosis. Of those that answered that it had not, some had not used the tool at all. Some GPs reported that they used the tool because they had a suspicion of cancer and used it to aid their decision to refer the patient or to reassure them that the risk was low. In addition to this, approximately 60% of responders highlighted that they had used the CDS Tool to help in their decision making on whether a patient needed further investigation.

"Sometimes it allows you to think of wider differentials, e.g. ovarian cancer when you were thinking of colorectal"
GP 4

"Helpful to sort out what type of cancer to look for first when symptoms are vague"
GP 5

Suggested Improvements:
GPs highlighted a number of areas for improvement to CDS Tools, focused around the evaluation of the Tool's effectiveness, and its scientific validity. The algorithms used are based on rigorous academic research led by Professors Willie Hamilton and Julia Hippisley-Cox, which should be reinforced when promoting and delivering training sessions to ease the question of scientific validity. There were also some comments on the tool's functionality with some GPs finding it cumbersome or confusing, particularly without the appropriate training. A number of GPs highlighted it was unclear what to do with the information that the CDS Tool gave them.

Some of the suggested improvements covered: a clearer focus on symptoms; including more risk factors; including more cancer types; and, further integration within EMIS.

It is encouraging to note that over the lifecycle of the project the survey findings demonstrate there has been an increase in training to support the adoption and awareness of the CDS Tool. The findings also highlight how the tool could support decision making in particular vague presentations.

Project 3 – Early identification of cancer risk factors identified using an electronic Cancer Decision Support Tool within a general practice in Gateshead

Background
The incidence of cancer in Gateshead is 438.1 per 100,000 pop, and the mortality rate for all cancers all ages 217.4 per 100,000 population.

While the coverage of HPV vaccination within Gateshead (90.8%) is higher than the England average (86.1%) smoking prevalence in the over 18s is worse (22.9% and 19.5% respectively) the <75 years mortality rate from cancer is higher in Gateshead than the England average (175.7 per 100,000 vs. 146.5 per 100,000).

While there is evidence that uptake of screening for cervical and breast cancers is relatively good in Gateshead when compared to the national average there is scope for benefit from earlier intervention targeted to groups at risk of developing breast, lung, colorectal, stomach, bladder and skin cancer.

Cancer incidence and mortality also show socio-economic gradients, with higher rates being associated with those experiencing greater disadvantage. The project was based in a GP surgery within the centre of Gateshead. A large proportion of the patients served by this practice will experience a high degree of socio-economic deprivation. The process of identifying patients through a CDS Tool, who may benefit from further medical investigation, hoped to narrow the inequity gap.

This work seeks to address the lack of symptom awareness, which applies to both affluent and disadvantaged groups but is more acute in the latter.

Project aims and objectives
The project sought to test the risk stratification function of the BMJ Informatica version of the CDS Tool (funded by Macmillan) in a GP practice in Gateshead.

The project aimed to evaluate the acceptability and utility of using a CDS Tool to detect patients at high risk of five types of cancer (lung, colorectal, pancreatic, ovarian and oesophago-gastric) and provide advice in a primary care setting or refer early for investigation as appropriate in order to diagnose cancer at an early stage.

Project results
The project ran from February 2015 to January 2016. Data were available for 100 patients. Technical issues and amount of time screening clinical records reduced the number of patients seen.

The pilot showed that a high number of patients were not suitable to attend the clinic as their medical records showed that they had already been referred under a 2WW rule, had a recent CXR or had been investigated and given the all clear in recent months. There were also a number of patients excluded from the clinic as they were housebound. A small number declined to attend the clinic following a telephone discussion. One patient had been diagnosed recently with leukaemia and two were in hospital.

The data profiled patients mostly on the lung cancer smoker list of the audit tool as this list generated the highest risk scores which had to be dealt with first. The colorectal smoker list was the category with the next highest risk scores, followed by oesophago-gastric.

Most patients attended and received a CXR or were referred to lower GI for 2WW investigations and happy to be investigated.

A quarterly check on those patients referred showed that of those investigated and /or referred none were diagnosed with the cancer under investigation. One patient was diagnosed with an unrelated cancer.

The initial patient experience questionnaire showed that 90% thought the reason for the appointment was clearly explained to them and 70% felt that being asked to come in made them feel nervous, anxious or on edge. 90% then stated that the doctor made them feel less nervous, anxious or on edge. 40% of people stated they felt worried about their health before they came in and 50% stated they were worried about their lifestyle before they were asked to come in. 80% thought telephoning them was the best way to contact them and nobody would have preferred a letter. The appointment was made at a suitable time for 100%.

The quarterly follow up questionnaires were not used due to time constraints and insufficient resource to be able to conduct and analyse the follow up questionnaire.

Technical issues with the risk tool led to delays in data collection and a reduced amount of patients seen. The BMJ Informatica tool was lost for several weeks due to a licensing issue which required a financial payment and other issues led to it not working at times – these have now all been fixed.

The pilot was well received by patients and satisfaction scores were high from the initial patient experience questionnaire. Arranging appointments was very time consuming and not a good use of GP time. A lot of time was spent looking at clinical records prior to patients being invited into the clinic, particularly due to the need to exclude large numbers due to them already having been seen at the hospital or been recently investigated.

To enhance the data collected here, the pilot could be extended to collect more patient data and ensure that conclusions are more robust. Additionally, selecting cases from each cancer groups would ensure that all are analysed equally. In response to the finding that arranging appointments was very time consuming for GPs; the use of other staff such as nurses could be trialled and potentially the clinic could be nurse led. Further work into the sensitivity/specificity of the Tool in excluding those who are already being or have been investigated would be interesting and help improvements in this area would help with implementation.

Key Findings

As a support tool, CDS Tools present evidence of being useful to GPs.

CDS Tools were able to help GPs when formulating their clinical decisions and also in reinforcing the decisions they had made. Comments from GPs strongly underline this view. In **Project 2** 60% of GPs stated that they had used the tool to help in their decision making regarding onward referral of a patient.

Project 1 showed that GPs were mostly utilising the symptom checker, not because the system was prompting them to, but because their own clinical judgment led them to choose to (in 75% of cases). This suggests GPs were finding it useful, and likely in cases where they were not immediately sure of a course of action.

Additional evidence of CDS Tools being useful as a support include the fact that in **Project 1** there was a very clear association between the risk score observed and the referral decision taken. Coupled with that, it was apparent that in no cases did a GP choose to not refer a patient for further care because of a low risk score, who later returned to the system to be diagnosed with cancer. In cases where a low risk score was observed and the patient received a cancer diagnosis, the GP had always correctly referred them onwards. This is very possibly because these cases were more clear-cut cancers such as breast cancer. Importantly, CDS Tools are not taking away the decision making role from the GP (as is a potential concern for the implementation of CDS Tools) and are only being employed as additional support to the GP's own decision making process.

CDS Tools can heighten a GP's awareness of cancer.

CDS Tools worked effectively to bring cancer to the front of GPs' minds during patient consultations, where they have a multitude of potential options to consider. **Project 1** displayed that in 82% of cases where the tool had directly influenced the management of a given patient, the GP stated that the tool had helped them to consider a cancer diagnosis as well as particular, specific investigations.

This kind of finding was clear across projects, with the GP survey carried out alongside **Project 2** highlighting that 34% of GPs commented that the CDS Tool particularly raised their awareness of a cancer diagnosis. Of the two thirds who said that the CDS Tool had not raised their awareness of cancer, many of them had actually not used the CDS Tool at all.

CDS Tools could help with decision making around complex patients.

An area where GPs may particularly find the support of a CDS Tool to be useful is in complex cases. For example, patients presenting with vague but concerning symptoms, or those with one or more underlying comorbidities. **Project 2**, which was particularly collecting data on comorbidities, showed that in 41% of all cases where the CDS Tool was used, the patient had at least one underlying condition – not including dementia. COPD was among the most largely represented comorbidities, and it is known to mask lung cancer. CDS Tools may have a potential use in helping to separate out the cancer risk from the underlying COPD symptoms. More research should be done around this, as due to the limited data collected around this from these projects a solid conclusion cannot be drawn.

In support of this, data collected in **Project 1** showed that the CDS Tool was most likely to influence a GP's decision making when a patient's risk score was either between 3 and 9.9 or above 20. Interestingly, the patients in the 3-9.9 risk category could be cases where it is less obvious to the GP what action to take, as they are on the borderline of being at high risk, thus knowledge of the risk score is more likely to be helpful to the GP. Further, the CDS Tool was also much more frequently influencing a GP's decision making when they used it during a consultation (as opposed to afterward) perhaps suggesting that GPs were choosing to utilise the CDS Tool fully during consultations in cases where they thought it may be able to actively aid their decision making.

In contrast to CDS Tools potentially being particularly useful in cases that are more complex, it is worth noting that they may not be as useful (or necessary) in cases where a patient presents with clear, red flag symptoms of a particular cancer. Therefore, if the GP is able to clearly see the correct referral route for a patient, they may not fully complete the risk calculation. This somewhat explains the low risk scores seen in some patients who are later diagnosed with cancer, having been appropriately referred by their GP.

Knowledge of the QCancer risk score can help to legitimise a GP's referral.

From both the GP's and the patient's perspective, knowledge of the risk score can help them to feel comfortable with whatever decision is being made. A high risk score can help the GP to feel confident in making a fast track referral; with many GPs pointing out that the score did help to reinforce their gut feeling. Additionally, a low risk score can be shared with the patient to give them peace of mind that they do not need an onward referral at this time.

Importantly, though the knowledge of a calculated risk score is helping GPs and patients to feel confident in and comfortable with the decisions being made, it is the GP's own clinical judgment that is making the decisions, with CDS Tools purely acting as useful supports.

The association between QCancer risk score and resulting cancer diagnosis is unclear.

In **Project 2** there were cancer diagnoses recorded following a risk score of less than 3. These were largely cancers such as breast cancer, where the CDS Tool did not to be as appropriate. At first glance it would suggest that the CDS Tool was missing these cancers, however, in all cases the GP did refer the patients onwards for a cancer diagnosis, so it is perhaps more likely that the GP was not completing the symptom checker as fully as in other cases because it wasn't needed in order to make the referral - thus explaining the lower risk score.

Although it was hoped that data from the projects could look into any association between the calculated risk scores and resulting cancer diagnoses, this proved to be particularly challenging. Across the projects only limited data linking QCancer risk scores with cancer diagnoses became available for analysis, and no data linking QCancer risk scores with cancer stage. The challenge of this was known at the outset, and the logistics of this would be worth considering for anybody hoping to complete research in this area.

Increased training and promotion of CDS Tools had a positive impact on GP uptake.

A survey carried out in parallel with **Project 2** demonstrated a clear increase in both the uptake and understanding of the CDS Tool being used across the period of the project. In the year the project was active, the proportion of GPs having received training increased from less than half to 85%. This aligned with an increase in the impact the CDS Tool was having on GPs' actions, with the proportion of GPs who had specifically found it useful in their decision making process increasing from 30% to 60%.

Whilst **Project 1** did not monitor training as such, it did note comments from GPs highlighting some misunderstandings with the CDS Tool and how its scores should be interpreted. For example, in one case a GP was surprised when a risk score of greater than 3 was indicative of a potential cancer diagnosis. Issues like this highlight the need for 2 things: increased levels of training around CDS Tools as well as, perhaps more importantly, working to make it as intuitive as possible. GPs should be able to use the tool without having to learn how to use it and significantly adapt their practice to fit it in.

Drawing across findings from both of these projects, where GPs were well informed on how the tool worked and what it should do, they were more likely to be able and willing to use it successfully.

No observed negative impact on patient experience following proactive risk stratification.

Patient feedback from **Project 3** reported high levels of patient satisfaction, with 90% of patients stating that their GP made them feel at ease. This project was focused on approaching patients at higher risk and inviting them to come in to visit the GP. This is something that would have felt unusual to the patient and is something that could have had a negative impact on patient experience if not managed carefully. Whilst patients did report feeling nervous around being asked to attend (70% of cases) they also reported being made to feel at ease by their GP, and felt that the reason they were being asked to attend the appointment was clear (in 90% of cases).

Projects using CDS Tools to risk assess presenting patients did not specifically measure patient experience. Ideally, their experience should have been fairly consistent with usual GP consultations. The only potential concern centred on the use of CDS Tools taking up too much time in the consultation, and therefore detracting from the Patient/GP relationship. This concern was raised by GPs through returned questionnaires during the span of the project. It wasn't raised in a large number of cases. Notably, more GPs reported finding CDS Tools useful in supporting their decision making than those who brought up concerns about the amount of time it was taking to use.

Additionally, it was reported by GPs that the QCancer risk score helped them to explain their clinical decision to patients. This was done through sharing the calculated risk score with the patient, helping them to understand decisions taken and feel more comfortable. For example, a patient with a risk score of less than 3 might be told that their risk of cancer was low and that an onward referral was not needed at that time; sharing the score with this patient may make them feel more at ease with this decision.

Consistency between findings presented in projects, previous literature and the UTAUT theory.

Bringing together previous literature and coupling it with the UTAUT model it was determined that some of the most important factors to consider when implementing tools such as these were: 'trusting the knowledge base', 'reducing threat to decision making' and 'retaining patient relationships'. These match with our findings across the 3 projects, and also help to suggest reasons behind some observations.

Projects showed that GPs were more frequently adopting CDS Tools post patient consultation – one justification suggested was GPs used CDS Tools during consultations only when they specifically thought it could be helpful. This could also be coupled with a desire not to threaten patient relationships as the symptom checker could be time consuming when used during the consultation.

Thinking about 'reducing threat to decision making' CDS Tools are not threatening or replacing GPs' clinical acumen in the decision making process. There are clear examples illustrating that the GP is happy to make their own decision based on the patient in front of them, whilst considering the calculations of a CDS Tool as a helpful support in that process where appropriate.

Consistency was demonstrated between the results seen here and those presented in the Macmillan CDS Tool evaluation presented in the introduction to this report. This is true particularly around the fact that the utility of CDS Tools were found to be in raising awareness of cancer and its potential symptoms with GPs, with a good number of GPs stating that CDS Tools helped them to make a referral decision which they may not have made without it. Also, an important consistent finding is that CDS Tools will not suit all GPs way of working.

Recommendations

1. The use of a CDS Tool should be encouraged as a support to clinical judgment and as a part of campaigns to increase awareness of cancer symptoms with GPs. In doing this it should be recognised that this will not be the preferred working style of all GPs. Consistent with NICE guidelines, the symptom checker prompt should appear at a risk score of 3%.

2. The utility of CDS Tools with more complex patients, where the GP might ordinarily find it challenging to make a clear referral decision, should be indicated as a main use for GPs.

3. Clarity regarding the design and remit of the CDS Tool being used should be considered as part of the training. Particularly focused on helping GPs to understand for which cancers and symptoms the tool is appropriate.

4. Concerns from GPs around the functionality of CDS Tools should be considered when it is updated. Particularly focusing on making its features as intuitive to use and understand as possible.

5. Effectiveness of CDS Tools should be further tested, considering a more defined cohort of patients with vague symptoms to clearly understand the impact of the tool on referrals for these patients. Diagnosis, staging and outcome data should all be recorded and made available for analysis to afford the most robust conclusions.

6. The effectiveness of CDS Tools at identifying high risk patients across different age groups should be further explored

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Contact ACE

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

The ACE Programme
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Abbreviations

2WW	Two week wait
BMJ Informatica	British Medical Journal Informatica
CDS Tool	Cancer Decision Support Tool
CDSS	Clinical Decision Support System
COPD	Chronic Obstructive Pulmonary Disease
CXR	Chest X-Ray
EMIS	Widely used primary care clinical computer system.
GP	General Practitioner
Lower/Upper GI	Lower/Upper Gastrointestinal
MRI	Magnetic Resonance Imaging
NAEDI	National Awareness of Early Diagnosis Initiative
NICE	National Institute for Health & Care Excellence
OGD	Oesophago-gastro Duodenoscopy
QCancer	Cancer risk algorithms developed by Professor Julia Hippisley-Cox
RAT	Risk Assessment Tool. Cancer risk algorithms developed by Professor Willie Hamilton.
USS	Ultrasound Scan
UTAUT	Unified Theory of Acceptance and Use of Technology

Appendices

Appendix A: Report on Patient Involvement

Patient involvement

The projects in this cluster sought to apply and embed the electronic Cancer Decision Support (CDS) Tool into general practice to firstly, support cancer awareness and improve cancer referrals and secondly, identify high risk patients. The aim of this cluster was to evaluate the impact of using the CDS Tool in general practice and identify how best to encourage and support GPs to adopt the CDS Tool into their daily practice. It is important to highlight that due to the nature of these types of projects patient involvement was limited. Project outputs were via the usage of CDS Tool and evaluated solely on the data collected from the CDS templates.

Project ID	Project Concept	Organisation	Patient involvement
A45	Retrospective audit of cancer diagnoses using CDS Tool	London Transforming Services Cancer Team	No
A29	Using the CDS Tool to drive improved conversion rates for two week wait referrals.	Tower Hamlets CCG	No
A48	Early identification of cancer risk factors identified using an electronic cancer decision support tool within a General Practice in Gateshead	Bridges Medical Practice, Gateshead	Yes – patient experience forms

There were initially four projects within the IT Tools cluster that were successful in being shortlisted for the ACE programme to use and evaluate the CDS tool. Due to the delayed integration into SystmOne project A15 was halted and excluded from the ACE programme.

London Transforming Services Cancer Team (A45) ran an audit of cancer diagnoses using the CDS Tool across London. This project intended to engage Patient Participation Groups (PPGs) at the practices that were taking part in the project to gain insights and patient feedback. They hoped to deliver a number of focus groups with patient members of the PPG to get feedback regarding their views about doctors using the CDS Tool. However, due to ethical issues and lack of resource and capacity; the focus groups did not commence and no feedback was gathered.

Bridges Medical Practice in Gateshead (Project A48) developed patient experience feedback forms which were completed when patients were initially asked to attend an appointment, and then three months after that appointment took place. Whilst this is primarily patient experience, these forms helped influence the design of the clinic and processes involved. These insights from patients helped determine the future developments of rolling out a similar project in the community. Patient information sheets were also created to explain the reason for being invited to an appointment, though it is unclear whether patients were involved in developing these patient sheets. The feedback from these forms suggests that the pilot was well received by patients, with 90% stating that their GP made them feel more at ease.

Appendix B: Unified Theory of Acceptance and Use of Technology

Unified Theory of Acceptance and Use of Technology (UTAUT) theoretical model: Mapping the Barriers and Facilitators to use of CDS Tools

The Unified Theory of Acceptance and Use of Technology (UTAUT)

The UTAUT synthesises eight behavioural models/theories, pulling together their significant elements. These models include the Technology Acceptance Model;[19] the Social Cognitive Theory;[20] the Theory of Reasoned Action and The Theory of Planned Behaviour[21] and Diffusion of Innovation Theory.[22] The UTAUT comprises of four main determinants of behavioural intentions and use behaviour. These are perceived usefulness (performance expectancy); perceived ease of use (effort expectancy); social influence; and the perception that organisational and technical support exists (facilitating conditions).[23]

The factors affecting use of CDS Tools, as outlined in the literature review given in the main body of this report (page 2), have been categorised under the headings of the UTAUT and are presented in Table B.1.

Table B.1: The facilitators and barriers to use of CDS Tools by GPs mapped against the UTAUT

UTAUT / moderating variable	Facilitators to use of a CDS Tool	Barriers to use of a CDS Tools
Performance expectancy.	• Agreement with recommendations from the CDS Tool, • Improved knowledge / professional development, • Usefulness in consultation, • Assists decision making, • Better quality of care, • Patient specific point of care information, • Facilitates patient discussion, • Embedded patient education, • Increased alertness / awareness, • Time saver.	• Lack of evidence on effectiveness, • Poor quality of information / messages, • Disagree with recommendations, • Prompts deemed of limited value, • Lack of time during consultations, • Elements of the CDS Tool not deemed useful, • CDS Tool not intuitive to use.
Effort expectancy.	• Ease of use.	• CDS Tool not intuitive to use, • Message fatigue / erroneous information, • Need to adapt personal practice, • Extra workload, • Altering the current practice workflow.
Social influence.	• *Nothing specific to social influence identified as a facilitator in the literature.*	• *Nothing specific to social influence identified as a barrier in the literature.*
Facilitating conditions.	• Fit within current workflow, • Provision of training,	• Reliability of the CDS Tool,

	• CDS Tool based upon the needs of the practice.	• Integration with current systems, • Computer / network issues, • Lack of computers, • Lack of an implementation plan, • Altering the current practice workflow, • Lack of standardised software, • Security concerns.
Gender.	• *Nothing specific to gender as a facilitator identified in the literature.*	• *Nothing specific to gender as a barrier identified in the literature.*
Age.	• *Nothing specific to age as a facilitator identified in the literature.*	• *Nothing specific to age as a barrier identified in the literature.*
Experience.	• *Nothing specific to experience identified as a facilitator in the literature.*	• Experience (computer literacy).
Voluntariness of use.	• Commitment to use.	• *Nothing specific to voluntariness of use identified as a barrier in the literature.*
Miscellaneous.	• Acceptance of technology, • Openness to use a CDS Tool, • External rewards / reporting, • Involvement in design and development, • Ability to make minor modifications to accommodate workflow, • Trust in knowledge base, • Developed by a trusted source.	• Threat to doctor / patient relationship, • Loss of reasoning and clinical autonomy, • Resistance to change.

From theory to intervention

The Cochrane Effective Practice and Organisation of Care group (EPOC)[24] was developed to review best practice across healthcare. The EPOC has developed a robust taxonomy of interventions to influence professional practice behaviours. This has led to a focus on achieving very high levels of precision in intervention design and testing. The interventions included within the taxonomy are outlined in Table B.2.

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Table B.2: Interventions to influence healthcare professional behaviour as per the Cochrane EPOC taxonomy

Name	Description
Distribution of educational materials.	Distribution of published or printed recommendations for clinical care, including clinical practice guidelines, audiovisual materials and electronic publications. The materials can be delivered personally or through mass mailings.
Educational meetings.	Such as participation in conferences, lectures, workshops or traineeships.
Local consensus processes.	Inclusion of participating professionals in discussion to ensure that they agreed that the chosen clinical problem was important and the approach to managing the problem was appropriate.
Educational outreach visits.	Use of a trained person to meet with professionals in their practice settings, giving information with the intent of changing practice. The information given may include feedback on the performance of the professional(s).
Local opinion leaders.	Use of professionals nominated by their colleagues as 'educationally influential' or 'opinion leaders'.
Patient-mediated interventions.	New clinical information (not previously available) collected direct from patients and given to the professional.
Audit and feedback.	Any summary of clinical performance of healthcare over a specified period of time. The summary may include recommendations for clinical action.
Reminders.	Specific information designed or intended to prompt a professional to recall information or perform or avoid some action to aid individual patient care.
Marketing.	Use of personal interviewing, group discussion ('focus groups') or surveys to address identified barriers.
Mass media.	Varied use of communication to reached a great numbers of professionals including trade publications, posters, leaflets and booklets.

EPOC, Effective Practice and Organisation of Care
Adapted from Johnson and May (2015)

Conclusions

The UTAUT is a useful model. Three barriers and seven facilitators as identified within the literature were not classifiable by the UTAUT. The UTAUT has been adapted to include 'beliefs' (as a moderating variable), 'involvement', 'trust in the knowledge base', 'threat to decision making and patient relationships' and 'external rewards'. The constructs of 'threat to decision making and patient relationships', 'performance expectancy', 'expected effort' and 'facilitating conditions' are suggested to have greater influence. The moderating variables and constructs of this adapted UTAUT should be considered when developing an escalation plan for the Cancer Decision Support Tool.