

1. What is a Cancer Decision Support Tool?

Cancer Decision Support (CDS) tools are an aid to clinical decision-making, to assist GPs in their decisions about whether to refer or request further diagnostic investigation, in patients where they believe there is a risk of cancer. The tools display the risk of a patient having a specific type of cancer; founded on analysis of a historic population cohort and their risk of having cancer based on a range of factors including symptoms, medical history and demographic data.

2. What is the Cancer Decision Support Tools project?

This project is part of the wider Prevention and Diagnosis programme of work at Macmillan. Our aim for this project is to support GPs clinical-decision making about cancer by making the electronic cancer decision support tool available to all GPs in the UK.

The original tool is based on two risk calculators for cancer: the Risk Assessment Tool (RAT), developed by Professor Willie Hamilton and Qcancer® developed by Professor Julia Hippisley-Cox. It originally focused on lung, colorectal, pancreatic, oesphago-gastric, and ovarian cancers, this list has since been extended– we have also produced a melanoma symptom checker which uses the NICE recommended 7-point weighted checklist for assessment of pigmented skin lesions.

These cancers were chosen based on the recommendations of our GP Adviser team, who felt them the most appropriate for the electronic tool and would most benefit patients diagnosed earlier.

Following a nationwide pilot in 2013 and further rollout in 2014 to test the feasibility of an electronic CDS tool, we are now working with the three main GP IT system providers to develop integrated versions of the tool within their systems, with the aim of rolling out the tool to all GPs in the UK.

3. Who is involved in the project?

The project is led by the Prevention and Diagnosis team at Macmillan Cancer Support. We worked in partnership with BMJ Informatica to develop the tool, and we are currently working with Emis Web, Vision INPS and TPP SystemOne to create integrated versions of the tool to sit within their systems.

4. Why are we undertaking this project?

England has relatively poor survival rates for cancer which has been linked to more advanced stage at diagnosis and delays occurring between onset of symptoms and start of treatment. Later diagnosis may be due to late presentation, delays within primary care or following referral to secondary care services. An average GP will see seven or eight new cases of cancer (excluding non-melanoma skin cancer) each year but will see hundreds, or possibly, thousands, of patients with symptoms that could possibly signify cancer. We developed the cancer decision support tool to help GPs identify patients with cancer.

5. How does the cancer decision support tool work?

Currently the tool works alongside the electronic system that runs at your practice.

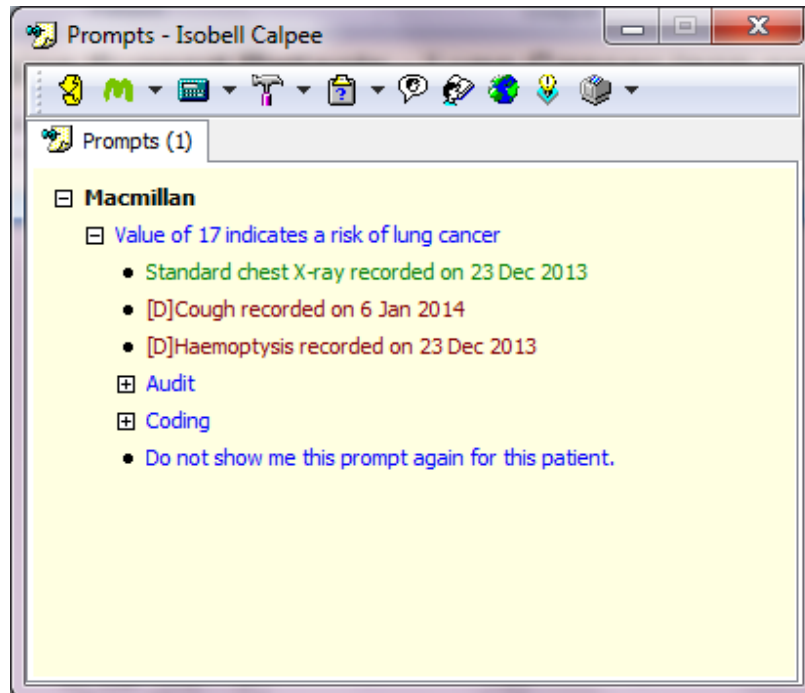
There are three functions to the tool: a *prompt*, a *symptom checker* and a *population risk stratification* function. We have included current screenshots of the tool below. Please note we are currently working with software providers to develop integrated versions of the tool, so the user interface is likely to look slightly different within each one – we will provide updates when available.

Prompts

This part of the tool calculates a patient's risk score by accessing demographic information about the patient via their patient record, relevant tests and read-coded symptomatic information from the previous 12 months to calculate a risk score in the form of a pop-up prompt when the patient's record is accessed.

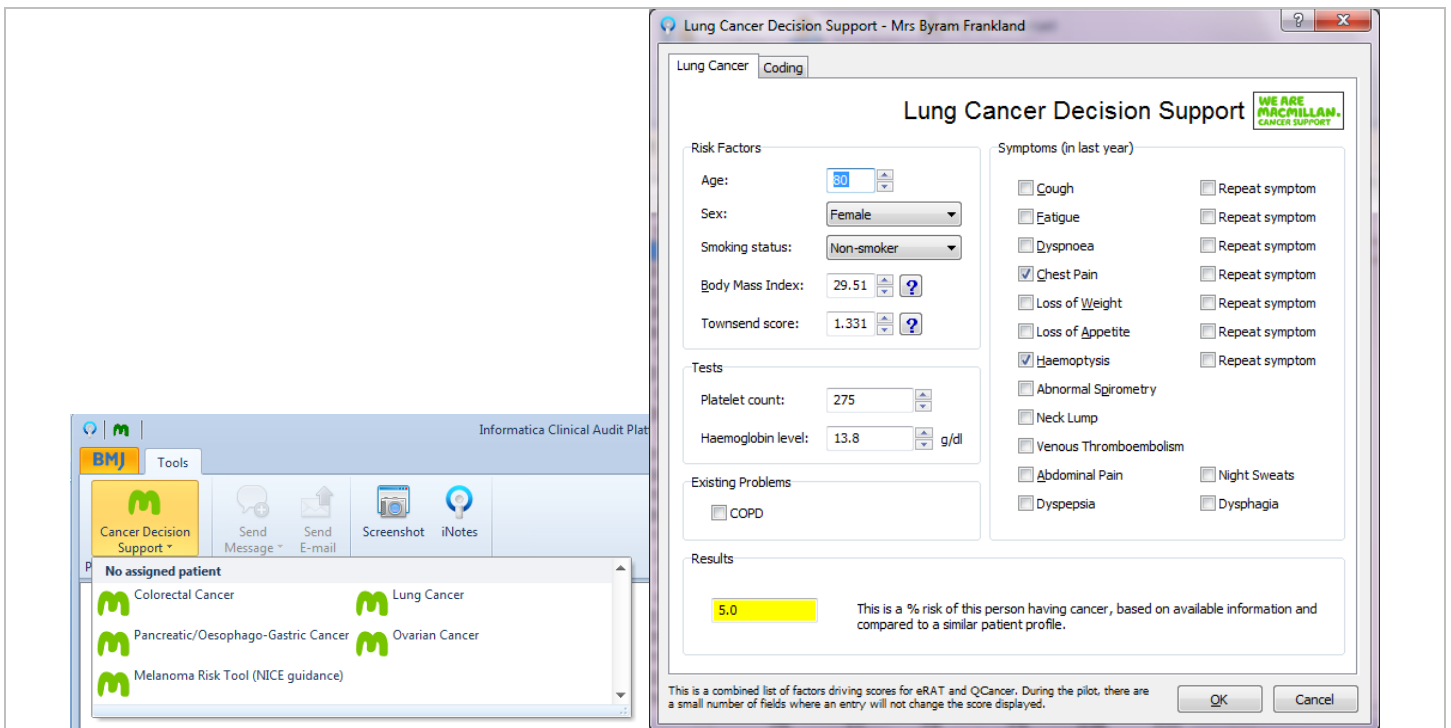
- If a risk of over 2% is calculated for any of the 5 tumour sites included in the tool, a prompt will appear on the screen.
- If there is a risk of over 2% for more than one tumour site then all relevant values will be displayed, sorted high to low.

The prompt function is useful for GPs in consultation where perhaps the likelihood of cancer is not immediately apparent, perhaps where a patient has seen a number of different GPs, or the symptoms displayed are non-specific. In order for the tool to drive the prompt function the patient must have relevant read-coded data within their patient record.



Symptom checker

This allows the GP to record a patient's additional and/or repeat symptoms during the consultation. For this to work, the GP must already think that the person has symptoms raising some concerns of cancer, and want to use the tool as an aid to clinical judgement in deciding a course of action. It uses symptomatic read codes to calculate a % risk score for that patient based on the symptoms presented as well as taking into consideration relevant read coded data and demography for the previous 12 months.



Population risk stratification

The population risk stratification function is not designed to be used in consultation. It's an administration tool which we envisage being used by practice managers or data analysts within the practice – it produces a list of patients for whom a risk has been calculated. The list can be sorted by risk so that, for example, the practice manager could see the patients for whom the risks appear highest based on the information in the patients clinical record.

Description	Patients	Actual %
Macmillan Cancer Decision Support	4170	
Lung Cancer (non-smokers)	241	5.8%
Lung Cancer (smokers)	419	10.0%
LCS01: PPV <= 1 (very low risk)	2/268	0.7%
LCS02: PPV <= 2 (low risk)	0/87	0.0%
LCS03: PPV <= 5 (medium risk)	2/53	3.8%
LCS04: PPV > 5 (high risk)	1/11	9.1%
Colorectal Cancer	1357	32.5%
Colorectal Cancer aged over 70	767	18.4%
Oesophago-gastric	387	9.3%
Pancreatic cancer	264	6.3%
Ovarian cancer	118	2.8%

6. How should the cancer decision support tool be used?

The tool can be used as a reminder to GPs to consider the likelihood of an individual patient having specific types of cancer. It's there to support GPs in considering whether further investigations or referral would be appropriate - an aid to clinical decision-making.

7. What do the risk values in the tool mean?

The risk values in the tool are the proportion of those people within the original study population, with the

listed characteristics and/or symptoms, who have that cancer type.

8. Will using the cancer decision support tool raise patient anxiety of the probability of having cancer?

These tools are designed only as an aid for GPs and they exercise their own judgement about how the tool is used in a consultation setting. Some GPs reported that a discussion about the level of risk can be useful as part of the consultation with patients about their symptoms. However, people have different perceptions of risk and for some it may increase their anxiety.

9. What does the tool actually look like?

The tool is computer-based and is integrated into the IT system your practice uses. It has three functions, a symptom checker, prompts and population risk stratification – see question 5 for a detailed description of the functions.

10. Why is the project focused on an IT solution?

This particular project uses an IT-based solution, as feedback from GPs suggested it would be the most useful way to access a clinical-decision making tool. It also allows us to draw on the historic READ-coded records held within the system, which enhances the power of enabling GPs to use it to aid their decision making.

11. Won't I find the prompts intrusive?

Feedback from the pilot suggested that there is a balance to be struck in determining the threshold at which prompts appear, and whether certain cases should be excluded from the prompt function. Currently the prompt function flags patients that have a minimum 2% risk of any of the tumour sites included in the tool. We will look to review the threshold at which the prompt appears with our Clinical Reference Group to help inform the software development. We have also considered the 2015 update for the NICE recommendations on suspected cancer referral.

12. Will the population risk stratification function be able to include specific high risk population groups?

The population risk stratification function allows users to sort by column. Including those identified as having high, medium, low and very low risk values (as calculated by the tool). Currently, the columns do not reflect more nuanced information on the identification of high risk population groups, but could possibly be something we explore at a later stage.

13. What national discussions have been held with secondary care regarding the potential for increased levels of referral and diagnostic activity?

It's hard to tell what impact the CDS tool will have on levels of referral and diagnostic activity, indeed this is one of the things we seek to measure as part of the project. Our focus for the pilot in 2013 was to see whether an electronic-CDS tool was useful for GPs in supporting their decision-making around investigation and referral. Whilst we are keen to measure referral impact going forward, this was not a focus of the initial pilot evaluation. We are currently exploring our options for further evaluation, and we will be linking with our colleagues in secondary care once we have agreed the plan and scope for evaluation.

Currently, our best guide is the previous desk-based RATs pilot. Evaluation of this pilot found that a total of 2593 RATs (1160 lung, 1433 colorectal) were completed. Compared with the preceding 6 months, there were 292 more chest X-rays, 104 extra 2-week chest clinic appointments, and 47 additional diagnoses of lung cancer. For suspected colorectal cancer, there were 304 more 2-week referrals, 270 more colonoscopies, and 10 more cancers identified. RATs appeared to help GPs in their selection of patients for cancer investigation. Users reported that RATs helped to confirm a need for investigation as

well as allowing reassurance when investigation was not needed.

14. How do these tools relate to NICE referral guidelines?

The 2015 NICE suspected cancer guidance (update) has been released, and states that patients with a positive predictive value of 3% or more require action (2WW or further investigation). The eCDS tool alerts the GP to patients with a positive predictive value of 2% or more, and is designed to pick up those 'low risk but not no risk' patients who sometimes fall outside the parameters of existing NICE guidance.

15. What evidence already exists for the use of cancer decision support tools in primary care?

This work builds on previous pilots of cancer decision support tools; such as the NCAT-led desk-based lung and colorectal tool, and Macmillan's IT-based lung and colorectal tool. The project itself is accompanied by a comprehensive evaluation, which can be downloaded from our [website](#).

My practice uses Emis Web – how do I download the tool?

We have worked with Emis Web to develop a version of the tool which is integrated into the system; it's similar to the original tool developed with BMJ Informatica and uses the Qcancer® algorithm. Emis have developed and released the symptom checker aspect of their Qcancer® tool with a full rollout expected to follow.

[Email us](#) to join the mailing list to receive notification when the integrated tool is available for Emis Web users.

16. My practice uses Vision INPS – how do I download the tool?

We are now working with Vision to build an integrated version of the tool within their system; it will be similar to the original tool developed with BMJ Informatica and uses the RAT (Willie Hamilton's Risk Assessment Tool) algorithm. This version of the tool will first be piloted in Scotland and then rolled out across the UK.

[Email us](#) to join the mailing list to receive notification when the integrated tool is available for Vision users.

17. My practice uses TPP SystemOne – how do I download the tool?

TPP SystemOne users can download the tool for free now via BMJ Informatica. [Email us](#) to find out more. We are also working with SystemOne to build a version of the tool which will be integrated into the system, and will be the same as the current BMJ Informatica version available.

[Email us](#) to join the mailing list to receive notification when the integrated tool is available for TPP SystemOne users.

18. I am a BMJ Informatica customer – can I use the tool?

BMJ Informatica customers can download the tool for free; the original version developed includes prompts, a symptom checker and access to the population risk stratification tool.

[Email us](#) to find out how you can access the tool.

19. What happens if the Practice changes their GP IT system?

As our tool will be compatible with all the major GP IT systems, this shouldn't be a problem as you will be able to continue using the tool within your new system.

20. Do all members of the Practice need to have the tool installed?

Only the staff members that require the tool need to have it installed on their workstation or user account.

21. How long will training take to complete?

We need approximately an hour to provide background information and a demonstration of the tool,

including time to answer questions and revisit any aspects of the tool or the presentation. We have two main ways in which we can provide training, either through a Webex (an online meeting tool we use to demonstrate the tool) or a visit to your CCG or GP event to demonstrate the tool to a wider audience. Please email us at preventionanddiagnosis@macmillan.org.uk to find out more or arrange a time for training.

22. What will the training cover?

Training covers three main areas of focus:

- i. General information about cancer decision support tools, the pilot we ran in 2013, how the tools work and how GPs can use them in practice.
- ii. Background information on the RAT and Qcancer®, how they were developed and how they calculate scores.
- iii. A walk through of the three main functions of the tool; prompts, symptom checker and population risk stratification.

23. Why are we concentrating on these tumour sites?

The decision to primarily focus on these five tumour sites (lung, colorectal, ovarian, pancreatic and oesophago-gastric) was taken following recommendations from our GP Adviser team and Clinical Reference Group; as the sites which would most benefit from early diagnosis and are challenging for GPs to deal with in terms of symptomatic presentation. They are also (mostly) not a current focus for established NHS screening programmes, and offer the greatest chance of earlier diagnosis for the largest number of patients.

24. What are the medico-legal implications of using this tool? Is the % risk score entered in the patient record?

This tool is intended as an aid to clinical decision-making, to reinforce and inform clinical opinion. GPs are not compelled to act on the basis of the scores displayed, but can consider if the score is useful in deciding a course of action for a patient. All the information driving the risk calculations is already present in the patient's notes. Risk scores calculated by the tool are not entered into the patient record at any point; the only amendment that can be made to records is the inclusion of symptoms entered through the symptom checker, added as the relevant/preferred READ code for that symptom. Previous pilots of both desk-based and IT based RATs have not led to medico-legal issues; additionally there have been no medico legal issues in the development, piloting and roll out of the e-CDS tool.

25. What proof is there of the tools' efficacy?

The CDS tool is built using algorithms from Qcancer® and RATs, and both have a weight of evidence behind them. Peer-reviewed articles on RATs have appeared in publications including the British Medical Journal and the British Journal of Cancer. Peer-reviewed articles on Qcancer® have appeared in publications including the British Journal of General Practice, the British Medical Journal, the British Journal of Cancer and the European Journal of Cancer Care. Evaluation of the 2013 pilot highlighted that of patients who were referred or intended for investigation, GPs reported that in around 20% of these cases they would have taken no action without the software. The tools were welcomed by the majority of participants because they raised awareness of cancer symptoms, reminding and alerting GPs to 'think cancer'. The tool was useful in practices where a patient may not see the same GP on each visit. In 2014, Macmillan also won a HSJ award within the category of 'Value and Improvement in Information Technology' in recognition of our work on the eCDS pilot.

26. At what % risk level will prompts appear?

Both RAT and Qcancer® calculate % risk scores from below 1% to a high level of probability. However, one of the main things we've learned from the pilot is the importance of setting prompts at the right level to be effective for clinicians to use. Too low, and an element of 'prompt fatigue' can creep in, too high and the aim of a tool designed to identify patients at 'low risk but not no risk' becomes compromised.

Our clinical reference group, which brings together opinion from a range of tool developers, academic GPs and Macmillan GP Advisors, has agreed that risks of 2% and over will generate a prompt. As we develop the tool further we will consider for each tumour site whether particular patient groups should have defined prompt thresholds or exclusions. For example, in our previous pilot we found we needed to consider how best to handle the patient cohort with COPD within the prompt facility for lung cancer, with this in mind the original BMJ Informatica version of the tool now considers COPD when assessing a patient's risk score for lung cancer.

27. What safeguards does BMJ/Informatica have in place with regard Information Governance?

All Informatica software is developed in compliance with the NHS standard ISB 0129. Clinicians are involved in reviewing software (including audits) to ensure risks are minimised and a panel of GP beta testers also test software prior to release to practices. For further information please see **Appendix A**.

28. Will the tool run in real time on the GP IT system?

Any information entered during consultation will be updated onto a patient's record during the practices' scheduled system updates - usually scheduled to happen overnight. So, whilst information entered on the symptom checker will change the score 'live' in front of you, if you enter information in the patient's notes you will not generate new prompts or see changes in the risk stratification scores until the system has updated.

29. Does the tool link to other patient management systems (e.g. Choose & Book)?

No. To help us capture information about the clinician's experience of using the tool, there is a section within the symptom checker which allows the GP to tick relevant information about tests that they have recommended. The tool is a standalone function that does not interact with any other patient or clinical management systems that may be in place. Clinicians will still need to book/schedule tests in the usual way, as per their practice protocol.

30. What is the threshold for smoking status?

Heavy smoker: 20 > cigarettes per day
Moderate smoker: 10>19 cigarettes per day
Light smoker: <10 cigarettes per day

31. Is there evidence that tool actually increases diagnoses of cancer that would have otherwise been missed?

The aim of the pilot was to see whether the eCDS tool raised awareness of cancer symptoms and made GPs "think cancer". From the evaluation report, we can see that this appears to have been the case in that a reported 19% of patients who were referred for further investigation would not have been if the tool had not been used. Whilst this is a relatively high figure, we are confident that these patients are being seen sooner along in the referral pathway than if the tool had not been used. Going forward, we would be keen to evaluate use of the tool and impact on referral rates and ultimately, cancer diagnoses. Our clinical reference group are currently deciding future evaluation plans with our research and evaluation team at Macmillan.

Until we are able to carry out further evaluative research, our best guide in this currently is the previous desk-based RAT pilot. Evaluation of this pilot found that a total of 2593 RATs (1160 lung, 1433 colorectal) were completed. Compared with the preceding 6 months, there were 292 more chest X-rays, 104 extra 2-week chest clinic appointments, and 47 additional diagnoses of lung cancer. For suspected colorectal cancer, there were 304 more 2-week referrals, 270 more colonoscopies, and 10 more cancers identified. RATs appeared to help GPs in their selection of patients for cancer investigation. Users reported that RATs helped to confirm a need for investigation as well as allowing reassurance when investigation was not needed.

32. With other similar tools used in primary care, risk stratification leads to a specific action (e.g. a care plan). Why put patients on a “risk list” using the risk stratification within eCDS without any evidence-based action to take as a result of the identified risk?

The full CDS tool is intended as an aid to clinical decision-making, to reinforce and inform clinical opinion. GPs are not compelled to act on the basis of the scores displayed, but can consider if the score is useful in deciding a course of action for a patient. All the information driving the risk calculations is already present in the patient’s notes. Risk scores calculated by the tool are not entered into the patient record at any point; the only amendment that can be made to records is the inclusion of symptoms entered through the symptom checker, added as the relevant/preferred READ code for that symptom. Previous pilots of both desk-based and IT based RATs have not led to medico-legal issues; additionally there have been no medico legal issues in the development, piloting and roll out of the e-CDS tool.

The specific population risk stratification function is not designed to be used in consultation. It’s an administration tool which we envisage being used by practice managers or data analysts within the practice – it produces a list of patients for whom a risk has been calculated. The list can be sorted by risk so that, for example, the practice manager could see the patients for whom the risks appear highest based on the information in the patients clinical record.

Appendix

A



IG Audit+.docx

Macmillan Cancer Risk Calculators

The Macmillan Cancer Risk Calculators are based on BMJ Informatica's iCAP/Audit+ technology and this document should be read in conjunction with the document covering Audit+.

The Cancer Risk Calculators are implemented as audits within Audit+ with some modifications to the user interface to accommodate the requirements of those reviewing the project. Some of the changes alter the data that is collected to enable the user experience and patient experience to be measured. This experience data is stored in the Audit+ database and transmitted along with risk score data and symptom data to BMJ Informatica servers hosted on N3 in a secure datacentre. None of this data can be related back to an individual patient as no patient identifying information is sent with this data. Cancer Research UK who are evaluating the project will download this data to help them with their evaluation.

Audit+

Audit+ is the basic product which underlies all the other BMJ Informatica products except Frontdesk. The other products introduce some variation and additional complexity which is dealt with in the specific documents for those products.

The overarching principle that all BMJ Informatica products adhere to is that as much processing as possible is done on the practice system so that only data that is specified to be sent outside the practice actually leaves the practice. In the standard default case no patient identifiable data leaves the practice and only numerical data is sent (this process is similar to the way QOF achievement reports are made to the QMAS system).

Practices with a local server or using hosted Vision

The diagram in appendix A illustrates the processes and flows when Audit+ is installed in a practice with a local server or a practice using a hosted Vision system (EMIS web requires different data flows which are discussed later).

Audit+ consists of a server component (which may be installed on the practice clinical system server or another machine) and a client component which is installed on user's workstations. The server component (everything inside the grey box on the diagram) should be included in the practices backup process however only limited amounts of historical data are retained within Audit+ and all patient data is refreshed nightly. The software is upgraded via the internet with messages being sent to users to show an upgrade is available. The server component upgrade requires user intervention to start the process to ensure this occurs at a time convenient to the practice. Once the server component has been upgraded (which normally takes less than 10 minutes) the client component is upgraded automatically when a user logs into the software.

To obtain data from the practice clinical system Audit+ uses a clinical data adapter which is specific to the clinical system in use. This connects to the clinical system via the API or other approved method and

extracts patient level data. The data adapter converts this raw data into a generic data stream which it passes to the audit analysis engine. This process enables the different data structures and coding systems in use in clinical systems to be processed in a consistent manner.

The data analysis engine takes the data from the data stream and analyses it in accordance with the audits installed in Audit+. The results of the analysis, which include patient identifiable data, are stored in the Audit+ database. Patient data that does not appear in the results of the analysis is not stored.

Users at the practice can access the results of an analysis via the client component of Audit+. This login can be password protected or can be associated with the user's windows logon at the discretion of the practice. Users can see lists of patients and the data that the audit has found. They may also (depending on the audit specification) see prompts when looking at a patient's record. These prompts enable data to be added back to the patient record to improve data quality and patient care.

An analysis is scheduled to run every night to update the Audit+ database and it is this overnight analysis which triggers any data transmission (ad hoc analyses which the practice may run do not trigger any data transmission). Data can be sent from the practice at two points; from the analysis engine and from the Audit+ database via the Output Aggregator. The default setup where Audit+ installations are associated with an Audit Central installation at PCT or CCG level is that after every analysis the numerical results are transmitted to Audit Central over N3. This data is just numerical and conveys information like numbers of patients with a particular condition, the numbers of patients with a condition who have had a specified blood test. No patient identifiable information is sent, only the practice can see which patients have been selected by the audit.

If non-numeric, patient identifiable data is required it can be transmitted from the analysis engine over N3 to a secure repository as defined by the customer. The data to be transmitted is defined by the audit and only the data specified is transmitted, all other data remains in the practice. The practice retains control over this transmission and can turn it off if they wish.

Practices using EMIS web

EMIS web uses a central hosted database and its different architecture requires a different approach to other systems. The data flows are illustrated in Appendix B.

In the case of EMIS web Audit+ is installed within the practice network (it cannot be installed in the EMIS web data centre) so all the data processing and transmission from the practice is unchanged. The difference is that the data stream comes from a remote system rather than the practice database.

To supply the data stream EMIS web transmits patient data across the N3 network to the iCAP Central Server. This stores the data in a holding database until it is collected by the iCAP agent installed on the practice network. The iCAP agent downloads the practice data to a cache within the practice network. This cache is then analysed by the iCAP/Audit+ analysis engine in the same way as for practices with a local server.

Testing

All BMJ Informatica software (including audits) is tested in house (this includes review by clinicians), and by a panel of GP beta testers before release to customers. Software is developed in accordance with the NHS standard ISB 0129 for clinical safety. In addition BMJ Informatica works with iSOFT/CSC and NHS

Connecting for Health to develop and test QOF rulesets each year prior to their release to other clinical suppliers.

FAQs

Q: Does BMJ Informatica have any information security accreditation?

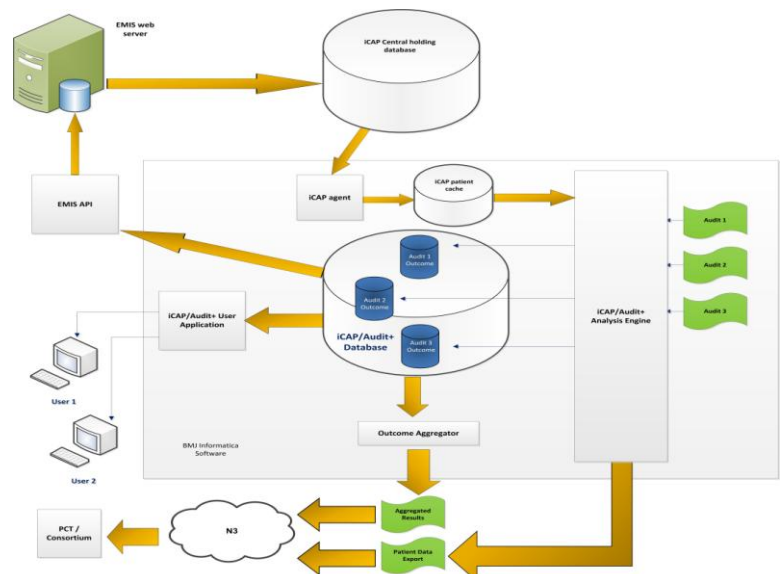
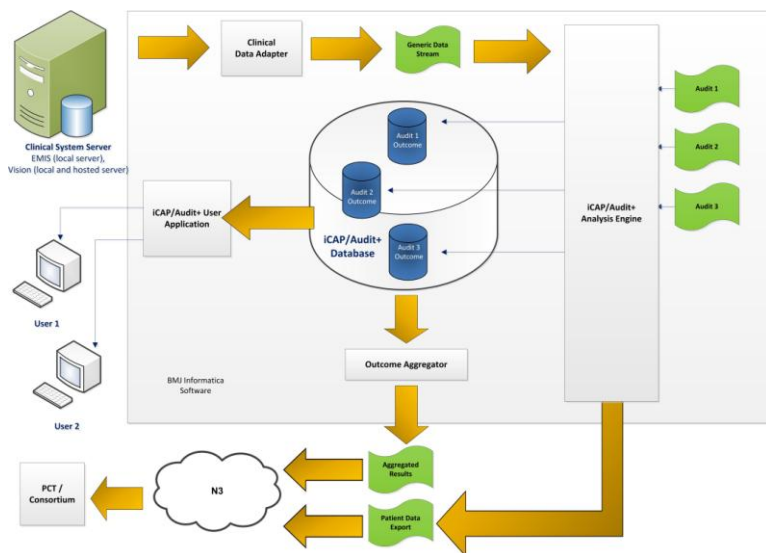
A: Yes we are accredited to ISO 27001.

Q: What happens if an audit needs to be changed for some reason?

A: We can make changes to audits and deploy them automatically to practices using them without any practice intervention needed.

Q: What are the security arrangements for iCAP Central?

A: iCAP central is hosted in a secure data centre approved for connection to the N3 network. The data centre has a secondary backup centre should there be problems with the primary centre.





FREQUENTLY ASKED QUESTIONS



Contact us: preventionanddiagnosis@macmillan.org.uk