THE MACMILLAN CANCER DECISION SUPPORT (CDS) TOOL

Supporting GPs clinical decision making for cancer

FREQUENTLY ASKED QUESTIONS
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What is the Cancer Decision Support Tool?

The Cancer Decision Support tool is a symptom based software which runs in parallel to a GP’s IT system and is designed to help GPs think cancer and to aid their clinical decision making. The tool supports GPs in their decisions about whether to refer or request further diagnostic investigation in patients with a risk of cancer. It displays the risk of a patient having an as of yet undiagnosed cancer, based on read-coded information pulled from their patient record including previous symptoms, medical history and demographic data, as well as using live data entered during consultation. It has three main functions:

- **Prompts**
  - For each patient with a cancer risk > 2%, a prompt appears with the patient’s tumour specific risk score and the reasoning behind it.

- **Symptom checker**
  - This is a tumour-site specific template with a list of potential symptoms for the GPs to select. A live risk score is calculated in consultation incorporating information from the patient record including previous reported symptoms or test results.

- **Risk stratification tool**
  - This tool calculates the risk level for each patient in a practice and allows the practice to review their population in order of risk for each cancer type.

The original tool is based on two risk calculators for cancer; the Risk Assessment Tool (RAT) algorithm developed by Professor Willie Hamilton and the QCancer® algorithm developed by Professor Julia Hippisley-Cox. The original tool focuses on lung, colorectal, pancreatic, oesophago-gastric, and ovarian cancers – this list has been extended in the EMIS QCancer® tool. 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 as they can exhibit vague symptoms.

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

Currently:

- The integrated QCancer tool is available for **EMIS Web** users in England and Wales.
- The integrated CDS tool is available for **INPS Vision** users across the UK.
- We are working with **TPP SystmOne** to develop an integrated tool and **INPS Vision** to roll their tool out across the UK.
Why should I use the tool?

The tool can be used as a reminder to GPs to consider the likelihood of an individual patient having an undiagnosed type of cancer. It’s there to support GPs to “think cancer” and acts as an aid in clinical decision making by encouraging GPs to consider whether further investigations or referral would be appropriate. The CDS tool is designed to help:

- Alert GPs to “think cancer”
- Raise awareness of cancer signs and symptoms
- Act as a patient safety net
- Aid continuity of care in practices where a patient may see multiple GPs

The CDS tool has been awarded the 2014 HSJ award for “Innovation and Value in Information Technology” and the 2015 HSJ Patient Safety Award for “Cancer Care” as well as winning the “Innovation” poster category at the 2015 RCGP conference in Glasgow.

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. Additionally, tick boxes in the symptom checker template act as a simple method of read-coding new symptoms, whilst also pushing this information back in to the patient file.

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.
How does the Cancer Decision Support Tool work?

There are three functions to the CDS tools: a prompt, a symptom checker and a population risk stratification function. We have included screenshots of each 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.

1. Prompts

This part of the tool calculates a patient’s risk score by accessing patient information 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 prompt which pops up as the patient’s record is accessed.

If a risk of over 2% is calculated for any of the five 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 the likelihood of cancer may not be immediately apparent, perhaps where a patient has seen a number of different GPs, or the symptoms exhibited 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.
3. 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.

2. 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 live in consultation based on the symptoms presented, as well as taking into consideration relevant read-coded data and demography for the previous 12 months.

QCancer® tool for EMIS Web users

We have worked with EMIS Health to develop the QCancer® tool which is integrated into EMIS Web; this tool uses Julia Hippisley-Cox’s QCancer® algorithm. The prompts alert a GP to a patient with a risk of cancer equal to or greater than 2% for any of the 12 cancer types currently covered by the tool. This includes blood, breast, cervical, colorectal, ovarian, uterine, lung, gastro-oesophageal, renal tract, prostate, testicular and pancreatic cancer. The alert prompt has been released in an inactive form to all EMIS Web users, and to receive these prompts you will need to activate the protocol which EMIS Web have added to their library. The QCancer® symptom checker template can also be found within the EMIS library.
How do these tools relate to NICE (NG12) or the Scottish Referral Guidelines for suspected cancer?

It is important to take into account that the calculation of PPV risk scores by the CDS tool differs slightly to that of the NG12 guidance, as this tool is not an electronic translation of the guidance. For this reason, the risk scores from the CDS tool are not directly comparable to the risk scores discussed in the NG12 guidance. In this way, although the CDS tool and NG12 guidance both discuss PPV risk scores, the evidence which drives the risk score differs, meaning that a 3% NICE PPV score does not directly correlate to a 3% CDS PPV score. However, whilst RAT calculates PPV, the QCancer® tool calculates a measure of absolute risk, meaning that a QCancer® score of 3% is equivalent to NICE risk score of 3%.

The CDS tool does not incorporate NICE or the Scottish Referral Guidelines for suspected cancer into the risk scores (although NG12 is based on similar evidence to that of the CDS tool) so it is not prescriptive to any guideline. Instead the tool is intended to complement all existing cancer guidelines by focusing not only on high risk patients but also those at low risk. In this way, the CDS tool can be used alongside all existing guidelines.

For more guidance regarding the 2015 NICE Update:
Macmillan has produced the ‘Rapid Referral Guidelines’ which is an interactive PDF summarising the 2015 NICE guidance for ‘suspected cancer: recognition and referral’. The Rapid Referral Guidelines also provides useful recommendations put together by the Macmillan GP community, for more information click here.

For more guidance regarding the Scottish Referral Guidelines for suspected cancer:
Please visit the Healthcare Improvement Scotland website to find out how to download the quick guide or new app.

What does a 3% risk score mean?

Due to the differing evidence base of the CDS tool when compared to NG12, a CDS risk score of 3% does not automatically mean that an urgent suspected cancer referral should be made. The risk scores in the CDS tool are intended to prompt the Primary Care Professional to “think cancer” and to consider whether further investigations or referrals should be carried out – in particular, when faced with a patient who has numerous vague or seemingly unrelated symptoms. For this reason, and because it is hoped that the tool can help to detect cancers in those patients that don’t necessarily fit the NICE guidance, the original Informatica tool is set to trigger an alert at a PPV of 2%.
What do I do if the patient has a risk score greater than 2% but does not meet referral criteria?

The CDS tool is designed to support the Primary Care Professional’s clinical decision-making and to encourage them to “think cancer”. For this reason, a risk score of 2% or more is not intended to prompt the Primary Care Professional into immediately referring the patient, but instead is intended to highlight the potential risk of cancer to them. By alerting the Primary Care Professional to the patient’s risk of cancer, the CDS tool thereby allows them to tailor their consultation and subsequent actions or follow-up to this possibility, if they feel it should be explored further.

What do the risk values in the tool mean?

The risk value generated from RAT are the proportion of those people within the original study population, with the listed characteristics and/or symptoms, who have that cancer type. QCancer® however is an absolute risk that the patient has a cancer that is as yet undiagnosed. For example, a QCancer® score of 3% means for a hundred people like you, three would have a cancer as yet undiagnosed.

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 Advisers, has agreed that risks of 2% and over in the QCancer® tool and INPS Vision CDS tool will generate a prompt. This threshold is open to review, 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, and with this in mind some versions of the tool now consider COPD when assessing a patient’s risk score for lung cancer.
What evidence is there that the tool works?

The CDS tool is built using algorithms from QCancer® and RAT, and both have a weight of evidence behind them. Academic papers supporting this research is available to view on our website.

During our 2013 pilot our aims were to explore the tool’s feasibility in daily practice and its efficacy with regards to patient management. The qualitative and quantitative data from the 2013 pilot evaluation show some promising evidence around the tools’ efficacy, with regards to use in daily practice and patient management:

• GPs reported that around 20% of patients who were referred for further investigation would not have been if the software had not been in place.

• GPs indicated that it succeeded in raising awareness of cancer symptoms, alerting GPs to ‘think cancer’.

Does the Cancer Decision Support tool increase cancer diagnosis?

No data has been collected yet regarding the impact of the Cancer Decision Support tool on clinical outcomes, therefore; at this stage it is hard to conclude that access to, or use of the CDS tool leads to increased cancer diagnosis or diagnosing cancers at an earlier stage. Our clinical reference group will decide on the next stages of the project’s evaluation with regards to impact on referral pathway. Additionally, we are in discussions with academics who are currently involved in evaluating the impact of CDS across England with the intention of collating and sharing their findings.

Until we are able to carry out further evaluative research, our best guide in this 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.
What are the likely implications of the Cancer Decision Support Tool on the number of referrals into secondary care?

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.

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 CDS without any evidence-based action to take as a result of the identified risk?

The full CDS tool is intended to support GPs in thinking cancer and act 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 the patient. All of the information driving the risk calculations is already present in the patient’s notes. Risk scores calculated by the original Informatica 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 preferred read code for that symptom. Alternatively, in the Emis QCancer® tool each GP can choose whether they would like to save the patient’s risk score back to their record or not as well as coding and pushing back symptoms entered through the symptom checker. 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 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.
S. Downloading the tool

My practice uses EMIS Health – how do I download the tool?

We have worked with EMIS Health to develop a version of the tool which is integrated into the system. The QCancer tool uses Julia Hippisley-Cox’s QCancer algorithm to produce a risk score based on the individual’s current signs, symptoms and risk factors.

We are pleased to announce that all EMIS Web users in England and Wales are now able to access this tool in EMIS Web 5.9, which includes risk score Prompts, the Symptom Checker template, an additional template to record QCancer Outcomes and Follow Up, and new Safety Netting searches. The alert triggering threshold has changed from a 5% composite risk score, to a site specific score of 2% or above.

For further information on how to activate the QCancer tool, please visit the EMIS Health support centre and log in using your EMIS Web credentials if based in England and your Support Centre credentials if based in Wales.

For further information, please email us.

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

We have been working with Vision to build an integrated version of the tool within their system; this tool is similar to the original tool developed with Informatica and uses the RAT (Willie Hamilton’s Risk Assessment Tool) algorithm. The Vision CDS tool alerts the GP to patients with a risk score of 2% or more for five different tumour sites: ovarian, lung, colorectal, oesophago-gastric, pancreatic. The tool sits within the consultation workflow and has three functions which are to provide risk indicator pop up alerts, data entry templates and practice reports. This version is now available to all Vision users across the UK.

Visit the INPS Vision+ Help page for a list of comprehensive FAQs and tutorial videos or email us for more information.

My practice uses TPP SystmOne – how do I download the tool?

The original CDS tool was developed with Informatica, and was previously available to TPP SystmOne users. However, following internal reorganisation within the organisation, Informatica have now made a decision to offer the CDS tool as part of one of their packages, rather than as a free download. For this reason, new TPP SystmOne practices are unable to download the original CDS tool.

We are currently working with TPP SystmOne to integrate the CDS tool into their system, so that it will be available free of charge to all SystmOne users without the need for a download. The integration process has been successfully completed with Vision and Emis Web, but as we are in the early stages of development with SystmOne, we do not as yet have a release date confirmed. If you would like your details to be added to the TPP SystmOne mailing list, so that we can update you when the integrated version of the tool becomes available, please email us.

I am an Informatica customer – can I use the tool?

If you are an existing Informatica customer, or would like to purchase a package to include the CDS tool before the integrated version becomes available, please email us.
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.

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.

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.
Will using the CDS tool raise patient anxiety on the probability of having cancer?

These tools are designed only as an aid for GPs who should 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, the GP should therefore use their personal judgement and knowledge of the patient to consider whether a discussion on risk would be helpful.

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 Informatica 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. For more information on how our tool relates to the 2015 NICE guidance for suspected cancer: recognition and referral please see Section 3.

What if I decide not to act on a risk score?

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.

Is the % risk score entered in the patient record?

Risk scores calculated by the original Informatica 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 preferred read code for that symptom. Alternatively, in the Emis QCancer® tool each GP can choose whether they would like to save the patient’s risk score back to their record or not. 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 rollout of the CDS tool.
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 this could possibly be something we explore at a later stage.
What other CDS resources are available to support me?

Visit our webpage [www.macmillan.org.uk/ecdsp](http://www.macmillan.org.uk/ecdsp) to find out more about the Macmillan Cancer Decision Support tool, including:

- Software integration updates
- Introductory video
- Monthly WebEx demo sessions
What other prevention and diagnosis tools are available to me?

**Significant Event Analysis**

Macmillan is currently working with RCGP and the NHS to help support GPs in carrying out cancer related Significant Event Analysis (SEA). SEA is a reflective technique which forms part of GP appraisals and is designed for GPs to learn from individual cancer cases to improve quality, identify good practice and learning points in primary cancer care. Currently data is being collected from Cancer Significant Event Audits from pilot sites across the country to develop an SEA training toolkit for practices to use locally to improve the quality of practice in primary cancer care.

To download the SEA template please visit: [www.rcgp.org.uk/clinical-and-research/our-programmes/quality-improvement/significant-event-audit.aspx](http://www.rcgp.org.uk/clinical-and-research/our-programmes/quality-improvement/significant-event-audit.aspx)

**Rapid Referral Guidelines**

The Rapid Referral Guidelines is a summary toolkit based on the 2015 update of the NICE guidelines for suspected cancer. This is an interactive PDF, designed by Macmillan GPs and GP Advisers for GPs and has been officially endorsed by NICE. For ease of use it is organised by tumour site, is designed to provide practical support, guidance and referral recommendations. This is now available to download onto your computer, mobile and tablet. The Scottish Referral Guidelines for suspected cancer can also be accessed from our website.

To find out more and download the guidance visit: [www.macmillan.org.uk/earlydiagnosis](http://www.macmillan.org.uk/earlydiagnosis)
Macmillan Cancer Risk Calculators

The Macmillan Cancer Risk Calculators are based on 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 Informatica servers hosted on N3 in a secure data-centre. 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 evaluated the project, will download this data to help them with their evaluation.

Audit+

Audit+ is the basic product which underlies all the other 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 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 users 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 or 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 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 Informatica is working with iSOFT/CSC and NHS Connecting for Health to develop and test QOF rule-sets each year prior to their release to other clinical suppliers.

FAQs

Q: Does 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.