CANCER DECISION SUPPORT TOOLS

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Frequently Asked Questions

November 2012

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 or not to refer or request further diagnostic investigation, in patients where they believe there is a risk of cancer. The tools in this project display the risk of a patient having a specific type of cancer; founded on analysis of an 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?**
   The plan is to support GPs in using an electronic cancer decision support tool 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.

   Macmillan is coordinating a first phase from February 2013 for six months, which will aim to test these cancer decision support tools in clinical practice and address any issues. This will ensure the development of valuable cancer decision support tools in electronic form, with firm evidence for their impact, and ensure they work across primary and secondary care as valid and defendable reasons for referral. Cancer Research UK has been asked to coordinate the evaluation of this project.

   The tool will focus in phase one on lung, colorectal, pancreatic, oesphago-gastric, and ovarian cancers. Macmillan's GP advisor community feel that these are the cancers which most lend themselves to such a tool, and which would most benefit patients who are diagnosed earlier.

3. **Who is involved in the project?**
   Macmillan is leading this project, which supports, the wider National Awareness and Early Diagnosis Initiative (NAEDI). This helps ensure alignment with other projects to promote earlier diagnosis of cancer, including the Department of Health's (DH) cancer awareness campaigns. Cancer Research UK, who are responsible for coordinating the evaluation of some of the NAEDI initiatives this year, are working to define the evaluation metrics and data collection methods for this project. The project has funding and oversight from the DH. Regionally, the project will be supported by your Cancer Network, who will co-ordinate recruitment of Practices and develop a local approach to training based on the core training documents and videos produced by Macmillan.

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 to delays occurring between the onset of symptoms and the start of treatment. Later diagnosis may be due to late presentation, delays within primary care or delays 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 be due to cancer. Cancer decision support tools have been developed to help GPs identify the one patient with cancer among the many who do not.

5. **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. The tool is used to support the GP in considering whether further investigations or referral would be appropriate. It is an aid to clinical decision-making.

6. **What do the risk values in the tool mean?**
   The risk values (positive predictive 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.

7. **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 GPs will be expected to exercise their own judgement about how they use these tools in the consultation setting. However, some GPs have 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. Other NAEDI activities are helping us understand patient and public views of cancer and the implications for awareness and early diagnosis.

8. **What is the role of practice managers in this project?**
   Practice managers will have a brief role at the outset of the project, in order that the software can be loaded remotely onto the Practice's computers. They might also be involved in providing a small amount of initial information on the Practice and its GPs, such as the GP IT system used, the list size, and number of GPs.

9. **What does the tool actually look like?**
   This project will use an IT-based tool which is integrated into your everyday GP IT system. The tool has three facets: firstly, the tool calculates a risk of having a specific type of cancer for every patient seen in consultation. If the risk is above a certain level, a prompt will appear on screen letting the GP know that the patient might warrant a referral or investigation for a suspected cancer. Secondly, a symptom checker can be called up, which allows the GP to enter relevant symptoms, and calculate a risk. Thirdly, an audit function can be used which will show calculated risk levels of all registered patients on a Practice's list.

   Participating GPs are encouraged to use all of these facets during the project. It is intended that the tool will be immediately useful in practice, and not too time-consuming or burdensome.

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

This project focuses on an IT-based solution, because feedback from GPs suggested that this would be a useful way in which they could access a CDS tool. We are building in functionality for a greater number of tumour sites, which lends itself to an IT solution. This approach also allows us to draw on the historic READ-coded records held within a GP IT system, enhancing the power of the tool.

11. Will I be able to use a desk based tool?

We do not want to stop GPs from using anything they already find effective. However, for the benefit of this evaluation, if your Practice falls within one of the pilot sites then only the IT version will be made available to you by your cancer network during 2012/13. This is to ensure that during the 6 month testing phase the evaluation is as robust as possible. If you are already using a desk based tool then we would encourage you to adopt the IT solution but this will be your decision.

12. Won't I find the prompts intrusive?

Feedback from our previous pilot of an IT-based tool 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. During this project we have the chance to make amendments, based on feedback. As well as initial careful consideration of how best to approach prompts for each tumour site, we will during the project, if necessary, adjust the level at which prompts appear to ensure they are useful and appropriate.

13. Will the tool work on my GP IT system?

We have agreed to build this tool during the testing phase, on BMJ Informatica software. Any GP Practice which holds a BMJ Informatica licence will see the CDS tool built into their existing software. Almost all other GP Practices will also be able to participate, as we have secured agreement with the major native GP IT providers that they will host the CDS tool as a software add-on. The add-on will start up automatically when you turn on your computer, and will run unobtrusively in the background.

14. Will the audit function be able to include specific high risk population groups?

The audit function allows users to sort by column. This will include columns for those identified as having high, medium and low risk values as calculated by the CDS tool. At this stage the columns do not reflect more nuanced information on the identification of high risk population groups. However, development of this software is an iterative process, and this is something that could be added at a later stage.

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

It is hard to tell what impact the CDS tool will have on levels of referral and diagnostic activity. The evaluation of the project will be interested in the use of diagnostics, and referral rates. It's clear that if the tool is to be successful it needs buy-in from secondary care, with that in mind the Department of Health will be writing to secondary care providers endorsing the project and asking for co-operation. Clinical and project leads from each of the participating cancer networks will also want to consider how they have these discussions locally.

16. How will data be captured for evaluation?

CR- UK is coordinating the evaluation of this project. This will consist of a quantitative and qualitative element. Evaluation is an important component of this project, with the

findings informing any future roll-out of the cancer decision support tools. We therefore very much value the input of participating GPs, though this will be kept to a minimum.

The intention is to draw wherever possible on standard routinely collected datasets, particularly in terms of measuring impact on investigations and referrals. In addition, functionality is being built into the tool to provide pseudo-anonymised data on use of the tools throughout the project. These data will be used to inform quantitative evaluation, and mean that we can collect data for evaluation without asking for direct input from participating GPs.

There will be a small number of specific questions for participating GPs to complete at the time of using the CDS tool, so we can gain insight into how GPs are using the tools and how they affect decision-making. Some qualitative information will be collected to further explore how the tools are used in practice and how they might be improved. In order to do this a small sample of participating GPs will be asked to volunteer some additional time to take part in a telephone interview lasting less than an hour.

17. What does signing up to capturing pseudo-anonymised data mean for GPs?

In terms of active engagement and additional workload, signing up to data capture will not have an impact on participating GPs. What GPs are agreeing to, is that they are happy for certain of their demographic characteristics such as gender and length of practice, to be captured in an aggregated, pseudo-anonymised form and used as part of our evaluation. One of the areas of focus for the evaluation is determining how these tools are accepted into practice, who uses them and how. These data will be invaluable in enhancing our understanding in this area.

18. What data will you collect as part of the evaluation?

We are still finalising our evaluation approach. At this point, we're proposing to collect for each patient an anonymised readout of their date of presentation, age, sex, signs/symptoms, and risk score. In addition, we want to collect some information about the GP (collected once, at the beginning), as well as GP responses about whether the score was higher/lower/the same as they had thought, how they were managing the patient, and whether they would have referred/investigated if they hadn't used the tool (collected through a small on-screen tickbox, completion of which each time will be optional though strongly encouraged).

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

These tools are designed to pick up those 'low risk but not no risk' patients who sometimes fall outside the parameters of existing NICE guidance. Some secondary care buy-in to the tool is necessary, as per FAQ 15.

20. 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. Learning from the evaluation[1] of these pilots is being used to inform the way in which this project is being approached. The project itself is accompanied by a

[1] A summary of the evaluation of the NCAT pilot can be found here: http://ncat.nhs.uk/sites/default/files/RAT%20pilot%20final%20report.pdf. A summary of the evaluation of the Macmillan pilot can be found here: http://www.macmillan.org.uk/Aboutus/Healthprofessionals/Primary_care_cancer_leads/Resources.aspx.

comprehensive evaluation, which will enable us to further build the evidence base for the use of these tools.

21. Has the project been ethically approved?

As this project can be defined as “Service Evaluation” according to National Research ethics definitions, ethics approval is not required. Ethical approval will be sought if required from the research organisation undertaking qualitative interviews as part of the evaluation.

22. Is the CDS tool compatible with Phoenix System One?

The tool has been designed to work with all GP systems including System One. The version 3 Read code database has been integrated into the tool thus allowing the CDS to run perfectly normally without any interference.

23. What is process for the tool to be installed at a Practice?

BMJ Informatica make an introduction call to the main Practice contact for the project (usually the practice manager or member of admin staff). Within that call they will ask a few questions so when the installation process begins it will quick and simple. BMJ will need to know:

- What date they can remotely install the tool.
- Who can assist BMJ with the installation? (This involves being at the chosen work station and reading a code to BMJ so they can remotely install the tool).
- If the PCT has locked down the surgery then they will need to be informed previous to the install date to allow BMJ Informatica access to the site.
- A list of users who require the tool and access to their machine.

24. Does the installation affect the Practice?

The remote installation does not affect the Practice in any way. The installation can also be done anytime throughout the day in accordance to the Practice wishes.

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

This is solved very easily. All the Practice need to do is call BMJ Informatica and they will remotely change the tool with no affect to the surgery.

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

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

27. How long will training take to complete?

The way that training is delivered by networks will vary. Some will use protected learning time or plenary events, others will engage with individual practices either in person or on the ‘phone.

Macmillan will develop a range of written and video-based training materials for cancer networks to use with their local practices. Time taken to undertake training will depend on the method of delivery used by the network. GPs will need to commit between one and two hours as a general guide.

Training materials will also be available online at the Macmillan website for the duration of the project, and Macmillan will run a webcast session to enable those GPs who couldn’t make network training to access facilitated online training.

28. What will the training cover?

Training will cover three main areas of focus:

i. General information about cancer decision support tools, how they work and how GPs should use them in practice.
ii. Background information on the RAT and QCancer, how they were developed and how they calculate scores.
iii. Detailed walk through of the IT, for each of the three ways in which the tool works.

29. Why are we concentrating on these tumour sites?

The decision to focus on these five tumour sites was taken by Macmillan's GP Advisor team; as the sites which would most benefit from early diagnosis, that are challenging for GPs to deal with in terms of symptomatic presentation, that are mostly not currently a focus for established NHS Screening programmes, and that offer the greatest chance of earlier diagnosis for the largest number of patients.

30. What happens after phase one of this project?

After phase one and its evaluation, if the findings are favourable these tools will be rolled out in a wholesale manner. If further controlled refinement and testing is needed, then Macmillan will lead on this work.

Macmillan is taking steps so that, if tools are to be rolled out wholesale, they will be available on a number of native IT providers as well as continuing to be available as part of the BMJ Informatica iCAP software.

31. Will I be able to use both QCancer and RAT?

The scores generated by QCancer and RAT will be made available through a single user interface. We feel it's important that everyone gets to use both calculators at some stage through the project, although we are unlikely to offer facility for GPs to see both scores for the same patient at the same time.

Our clinical reference group, with a robust evaluation in mind, will make the decision on how to assign use of QCancer and RAT to practices. Options that are under consideration at this stage include random assignment of QCancer or RAT scores for each individual patient, or a system whereby practices within a network are assigned use of one score calculator for the first half of the project, before swapping halfway through.

32. 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 are merely able to consider the score, if useful, in deciding a course of action for a patient.

PPVs for patients are not entered into the patient record at any point, the only amendment that is made to patient records is if symptoms have been entered when using the symptom checker then a READ code for this symptom will be automatically added to the patient's notes.

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

Both QCancer and RAT have a weight of evidence behind them. Peer-reviewed articles on RAT have appeared in a range of publications including the British Medical Journal, and the British Journal of Cancer. Peer-reviewed articles on QCancer have appeared in a range of publications including the British Journal of General Practice, the British Medical Journal, the British Journal of Cancer, and the European Journal of Cancer Care.

34. At what % risk level will prompts appear?

Both RAT and QCancer can calculate % risk scores from below 1% to a high level of probability. However, one of the main things we've learned from our previous pilot of an electronic version of the RAT, is that it's important to set 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, will discuss and agree appropriate prompt levels. For each tumour site we will consider 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.