London Cancer and Macmillan:
A guide to good quality coding and safety-netting

July 2015
EMIS Web v3
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1. Foreword

This guide to quality coding and safety-netting aims to enhance patient safety by having the most up-to-date and connected information about your patient at your fingertips, regardless of how long you have known the patient.

This quality improvement initiative will lead to more meaningful results from risk assessment tools, like QCancer. Together, these processes will reduce misses, lead to earlier cancer referrals and early detection, as well as improved screening and care for patients who have survived cancer.

There are no standards to coding and safety-netting at present.

In primary care coding has been defined by the Quality and Outcome Framework (QOF), prompting usage of specific codes which in turn produce payments for the surgery. In this guide, I will look at coding beyond the financial need alone.

The quality of input – determines the quality of the output.

2. Background to coding

History of Read codes
The Read code system was developed in the early 1980s by Dr James Read, who was a GP in Loughborough, to handle the problems of recording information in a way that could be retrieved from the computers available to GPs at the time. In 1989, as the importance of the system became clear and the number of codes rapidly expanded, it was purchased by the NHS Executive for further development, and to provide a uniform set of codes and terms to be used throughout the NHS. The Read codes have now been renamed the NHS Clinical Terms, although everyone still calls them Read codes or Read terms.

What are Read codes?
They are a comprehensive list of terms intended for use by all healthcare professionals to describe the care and treatment of their patients. They enable the capture and retrieval of patient centred information in a computer-based clinical language.

What do Read codes cover?
The Read code covers such topics as occupations, signs and symptoms, investigations, diagnoses, treatments and therapies, drugs and appliances (and more).

The structure of the Read code system
The Read codes exist in a hierarchical structure that looks like a family tree. They are arranged in chapters.

Read codes in primary care electronic healthcare record software
Free-typing the first few letters of a word, will auto-predict a drop-down list of words that may correspond to what the user is trying to free-type and these are Read-coded (it is similar to the predictive text on your mobile phone). The clinician can then select a Read coded word from the drop-down option. Sometimes there may be multiple Read codes for a single problem and it can be confusing to decide which Read code to pick. This is historical and means the user will have to be more vigilant when choosing Read codes. I will elaborate on this further in the manual.
3. What and how to code?

Code the problem title
This is putting a heading to your consultation entry, which captures the essence of the consultation. Headings act as signals for the reader and help them to organise and comprehend better what they are reading.

To watch a video on how to code a problem title click here.

Use Symptom codes
Choosing the most relevant problem code is important to make data fit together, so patterns and connections can be made. Traditionally clinicians apply diagnosis codes to their consultations and this ties in with QOF payments too. The reality is that many interactions are likely to be around a symptom and the diagnosis comes later (or not). Cancer symptoms can be notoriously non-specific which is why it is difficult to pick up some cancers early (e.g. ovarian cancer).

The NICE guidelines (revised in June 2015) regarding referrals for suspected cancer is primary care-focused and reveals a drive towards investigations and referrals for more non-specific symptoms (e.g. bloating). Cancer risk assessment tools, like QCancer, rely on symptoms to be coded over a period of time for the tool to be able to calculate a risk of cancer that is meaningful for the clinician. In order to improve the early detection of cancer in primary care, clinicians need to reflect more about the relevance of traditionally non-specific symptoms and read code them accordingly. This will assist to link clusters of symptoms together prompting more rapid investigations and cancer referrals.

Not just diagnosis codes – but Symptom codes.

As mentioned earlier, there are multiple codes for a seemingly simple problem. In general, it is advisable to pick the higher up code that fits the presenting problem. For example: Abdominal Pain – choose the first option Read code - 1969.

Figure 1. Screenshot of EMIS Web displaying the symptom code hierarchy for abdominal pain
Below is a list of prudent symptoms with their suggested Read code use. These codes are used in the QCancer risk assessment toolkit. QCancer relies on coded symptoms in order to calculate a risk.

<table>
<thead>
<tr>
<th>Presenting problem</th>
<th>Read code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appetite loss</td>
<td>1612</td>
</tr>
<tr>
<td>Abnormal weight loss or unexplained weight loss</td>
<td>1625</td>
</tr>
<tr>
<td>Abdominal pain</td>
<td>1669</td>
</tr>
<tr>
<td>Abdominal swelling</td>
<td>R0930</td>
</tr>
<tr>
<td>Difficulty swallowing liquids</td>
<td>1943</td>
</tr>
<tr>
<td>Difficulty in swallowing solids</td>
<td>1942</td>
</tr>
<tr>
<td>Indigestion symptoms</td>
<td>195</td>
</tr>
<tr>
<td>Heartburn</td>
<td>1955</td>
</tr>
<tr>
<td>Cough</td>
<td>171</td>
</tr>
<tr>
<td>Change in bowel habit</td>
<td>19EA</td>
</tr>
<tr>
<td>Constipation</td>
<td>19C</td>
</tr>
<tr>
<td>Painless rectal bleeding</td>
<td>196C</td>
</tr>
<tr>
<td>Painful rectal bleeding</td>
<td>196B</td>
</tr>
<tr>
<td>Blood in vomit – symptom</td>
<td>1994-1</td>
</tr>
<tr>
<td>Blood in sputum - haemoptysis</td>
<td>172</td>
</tr>
<tr>
<td>Blood in urine</td>
<td>1A45</td>
</tr>
<tr>
<td>Lump on neck</td>
<td>21IA</td>
</tr>
<tr>
<td>Night sweats</td>
<td>1662-2</td>
</tr>
<tr>
<td>Spontaneous bruising</td>
<td>1683</td>
</tr>
<tr>
<td><strong>Male:</strong></td>
<td></td>
</tr>
<tr>
<td>Testicular lump</td>
<td>2659</td>
</tr>
<tr>
<td>Pain in Testicle</td>
<td>1A57</td>
</tr>
<tr>
<td>Cannot pass urine - retention</td>
<td>1A32</td>
</tr>
<tr>
<td>Urinary frequency</td>
<td>1A1-3</td>
</tr>
<tr>
<td>Nocturia</td>
<td>1A13</td>
</tr>
<tr>
<td>c/o erectile dysfunction</td>
<td>1D1B</td>
</tr>
<tr>
<td><strong>Female:</strong></td>
<td></td>
</tr>
<tr>
<td>Postmenopausal bleeding</td>
<td>1583</td>
</tr>
<tr>
<td>Irregular menstrual bleeding</td>
<td>K594</td>
</tr>
<tr>
<td>Post-coital bleeding</td>
<td>K597</td>
</tr>
<tr>
<td>Breast lump</td>
<td>1A8</td>
</tr>
<tr>
<td>Nipple discharge symptom</td>
<td>1A9</td>
</tr>
<tr>
<td>Deformation of breast</td>
<td>268A</td>
</tr>
<tr>
<td>Persistent mastalgia</td>
<td>26BF</td>
</tr>
</tbody>
</table>

**ADDITIONAL SYMPTOMS**

| Diarrhoea                              | 1952      |
| Diabetes (new onset)                   | **Use the usual codes. Link to pancreatic cancer in those with additional symptoms (diarrhoea, back pain, abdominal pain, nausea etc.)** |

Table 1. List of top-tier symptom Read codes
To watch a video demonstrating how the integrated QCancer risk assessment tool in EMIS Web operates and is dependent on symptoms codes click [here](#).

**Symptom coding within a consultation**
The extent of Read coding within the consultation is not uniform and varies. Coding of physical parameters like blood pressure or weight would be coded by most physicians. What if we coded more data within the consultation? Coding the problem title has a clear advantage for users and is easy to do. Coding symptoms within the consultation may be perceived as more laborious and with less tangible gains. But coding within the consultation can be faster and easier, and the benefits could be dramatic, not only for the user but for researchers too.

To watch a video demonstrating how to code symptoms within a consultation click [here](#).

**Ensuring the Problem code is saved under the most suitable category**
When saving a consultation there are options to categorise the entry. For example, *shortness of breath symptom* is saved as a *clinical problem* and is *active* and could be *review*.

To watch a video demonstrating how to categorise consultation entries click [here](#).

**Cancer diagnosis**
Diagnosis of cancer should always be an *active problem* *indefinitely*. This should be applied to patients who have cured cancer or have long periods of being cancer-free. This is because these patients have an increased risk of a recurrence or a second cancer. It also helps reduce the chance of the diagnosis of cancer being missed when a patient moves surgery and sees a new set of clinicians.

**Patient history codes**
Patient history codes which are recommended at new patient checks or ad hoc in the consultation, if it has not been captured before:

- Code: *smoking* history
- Code *weight* – as only way to audit it and see if accurate weight drop – use electronic scales if possible
- Code any *family history of cancer* – either by typing into consultation or using the QCancer template

![Figure 2. EMIS Web screenshot demonstrating how to code family history of cancer in the consultation entry](#)
Figure 3. EMIS Web screenshot demonstrating how to code family history of cancer in the QCancer template

**Coding urgent cancer referrals**
The Read codes do not have *two-week-wait* and *fast-track* is the alternative naming system. This way you can audit your own referrals and see your own practice profiles rather than wait for practice profiles to be uploaded on the cancer toolkits e.g. *fast-track breast*.

Figure 4. Coding *two-week-wait* as *fast-track* cancer referrals in EMIS Web. There are *two-week* rule codes on EMIS Web however these are EMIS-only codes and are not transferable to other systems.

**Screening engagement and non-attendance**
Screening engagement and non-attendance can be captured through appropriate coding which would enable tracing of non-attenders. The national programmes include cervical, bowel and breast screening. The variation in how screening data is processed varies much in general practice. It depends on who is responsible for coding and what systems are in place.

**Cervical screening:**
- Smear results can be sent as a paper result which gets scanned. They should be coded appropriately in order to have accurate data on non-attenders.
- Smear result that come through electronically still require coding as the code applied is only to say smear was done.
- An appropriate comment should be applied to the result (e.g.: abnormal smear), so this will sit in the consultation page and can be more easily picked up by any clinician seeing the patient.
- A diary entry should be created or modified to ensure robust follow-up and it should reflect the correct follow-up depending on the patient’s background (e.g. once a year or every three years).
Patients with abnormal cervical cytology results are automatically contacted by the local trust for further action, but if coded in a timely manner patients who have been missed can be contacted. This is particularly prudent to be able to capture transitional patients who move GP surgeries frequently.

Reminder letter are sent to patients from the screening service. GP surgeries also send reminders.

By Read coding and commenting on results then clinicians can act ad hoc to prompt patients or actively run more accurate searches on non-attenders?

<table>
<thead>
<tr>
<th>Cervical smear taken</th>
<th>7E2A2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cervical smear: inadequate</td>
<td>4K21</td>
</tr>
<tr>
<td>Cervical smear: negative</td>
<td>4K22</td>
</tr>
<tr>
<td>Cervical smear: HPV positive</td>
<td>4K2R</td>
</tr>
<tr>
<td>Cervical smear due</td>
<td>685F</td>
</tr>
<tr>
<td>Cervical screen: action req.</td>
<td>4K4</td>
</tr>
</tbody>
</table>

Table 2: Relevant codes related to cervical screening.

Figure 5: Follow-up codes for cervical smear

**Bowel screening:**

- The majority of GP surgeries should receive bowel screening data electronically (through the same system as the pathology links). The faecal occult blood test (FOBt) result is therefore already attached to an appropriate Read code.

- Some CCG areas have non-responders flagged up automatically in the EMIS pop-up alerts on the bottom right hand corner of the screen.

- If the surgery receives paper notification of bowel screening results, then these should be scanned and then coded appropriately in order to have accurate data on non-attenders. Electronic screening notification is clearly preferable; to enable this, the surgery could contact the local screening hub to check if this is available.

- An appropriate comment should be applied to the result (e.g.: abnormal smear), so this will sit in the consultation page and can be more easily noticed up by any clinician seeing the patient.

- By read coding and commenting on results then clinicians can act ad hoc to prompt patients or actively run more accurate searches on non-attenders?

- The Bowel screening programme in England currently invites men and women every two years from 60 to 75 years old (extended from 70 to 75 years). GPs could play a role in advising above the invitation age to self-refer.

<table>
<thead>
<tr>
<th>BCSP: Faecal occult blood test normal</th>
<th>686A</th>
</tr>
</thead>
<tbody>
<tr>
<td>No response to bowel screen invitation</td>
<td>9Ow2</td>
</tr>
<tr>
<td>Bowel scope (flexi-sig) screen: normal – no further action</td>
<td>68W21</td>
</tr>
</tbody>
</table>

Table 3: Relevant codes related to bowel screening
Breast screening:
- Most practices receive paper notification of mammography results; these should be scanned and Read coded appropriately in order to have accurate data on non-attenders.
- An appropriate Read code should be applied to the result so that it sits within the entry and can be easily noticed by any clinician seeing the patient.
- By Read coding and commenting on results clinicians can either counsel patients within the consultation for screening or run regular more searches on non-attenders.
- The breast screening programme in England currently invites women for screening every three years up to the age of 70 years old. The NHS cancer screening programme will extend this to 73 years by 2016. GPs could play a role in advising women above the invitation age to self-refer to the breast screening programmes.

<table>
<thead>
<tr>
<th>Breast screen non-attender</th>
<th>9OHC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast screening offered</td>
<td>9OHF</td>
</tr>
</tbody>
</table>

Table 4: Relevant codes related to breast screening

Cancer care in the community: Living with and beyond cancer
Cancer is increasingly being considered a chronic disease and patients are gradually surviving cancer or living with stable cancer. In this climate of disease management change, general practice will be required to adapt to manage cancer patients in the community. The care provided should align with other chronic disease management (like diabetes) and managed holistically. Work-streams to develop support and education for primary care will be required, and coding of this information will form the foundation of good practice.

The cancer care review (see figures 5 and 6) are already present but this the amount of data and relevant data captured is very limited. Work is being done by other bodies to create templates to capture disease and management information and action paths.

Recommended coding for cancer and management:

<table>
<thead>
<tr>
<th>Radiotherapy NEC</th>
<th>7M371</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chemotherapy</td>
<td>8BAD</td>
</tr>
<tr>
<td>No evidence of recurrence of cancer</td>
<td>1I20</td>
</tr>
<tr>
<td>Radiation proctitis</td>
<td>J574E</td>
</tr>
<tr>
<td>Postmastectomy lymphoedema</td>
<td>G860</td>
</tr>
</tbody>
</table>

Table 5: Cancer treatment and complication codes.

Figure 6: Cancer templates in EMIS Web by searching in templates
New registrants
When a patient registers with a GP surgery their electronic and paper notes are transferred to the new surgery. Electronic transferring (known as GP2GP) works well when the exchange is between similar systems because the notes integrate as a seamless set of electronic notes. But if data is being transferred from Vision to EMIS, then notes get filed as a large attachment which results in a loss of previous Read codes. The exchange of paper notes wholly or partly requires summarising. There is a lot of data, including cancer data that could be missed or misfiled or not coded. Having a standard for summarizing this data may be useful (in the additional section you can find an example of this).

Docman coding
Intelli Sense is a function on Docman which can be used to Read code and these are compatible with EMIS. Many surgeries in London are using Docman to scan documents. This is another area where there is much variability on what data is coded. Having a protocol or a designated pathway for coding through Docman would ensure any important information about patients is Read coded.

Coding is much faster and easier than it is perceived to be.

4. Safety-netting

Safety-netting is a process where people at low-risk (but not no-risk) of having cancer are actively monitored in primary care to see if the risk of cancer changes. The concept was introduced to general practice by Roger Neighbour who considered it a core component of the GP consultation. Safety-netting is considered to be a core aspect to the GP consultation, yet there is virtually no guidance and very few formal documents on it.
In 2011, the Oxford Department of Primary Health wrote a report entitled Cancer Safety-netting Report. It was comprehensive and they recommended a strategy for safety-netting. The highlights have been collated here. The theory and models behind safety-netting are well established, and most clinicians are aware of these (e.g. Calgary-Cambridge model for consultations). But specific recommendations of what exactly to do have been lacking. This guide arranges and prioritises the different components of safety-netting, and the methods used to safety-net in relation to cancer diagnosis in primary care (though these can be very easily applied to other diseases). The guide sets out practical steps which can be adopted very easily into daily practice. The ideal aim is to ensure safety-netting has occurred and documented through coding or other electronic means.

The guide reviews various methods, current tools and the numerous stages of safety-netting operationally. It also considers the GP, patient and practice actions within the safety-netting process. There is much variation in methods
used to safety-net because the process is dependent on the clinicians, management and systems within the practice. Factors such as population size, the number of clinicians, technology utilisation and number of administrative staff will impact how and which methods are used.

**Methods of safety-netting**

![Figure 8: Highlights a range of examples and methods of safety-netting used within a consultation](http://www.marketingsherpa.com/article/interview/six-scientifically-proven-ways-to)
**Stages of safety-netting**

The below actions are recommended for a patient when the GP has reasonable concerns. These actions should be undertaken by either the GP, patient or support staff at different levels of the patient’s journey.

At the **first consultation** the GP should:
- Give the patient clear oral and written instructions.
- Book the follow-up appointment.
- Ensure that the patient’s contact details are correct, and that their mobile number is documented.
- Send him/herself a patient task to remember to follow-up with the patient.
- Ensure that the patient understands how and where to go for investigations, and how to get any results.
- Document and code follow-up (9N7).

With the **same problem after several consultations** the GP should:
- Implement investigations for recurring and/or unresolved problems.

During the **investigations** process the GP should:
- Tell the patient to chase results within a reasonable timeframe and told how to do so.
- Not rely on patient calling - significant result recall should be in place.
- Relay significant results urgently and in person or telephone.
- Document their recalls and any failed recalls.
- Keep electronic list of worrying results.
- Ensure pathology comments are suitable, and that reception staff can understand them.

During **communication with the hospital**, the GP should:
- Check their local hospital pathology and radiology policies regarding how urgent results are communicated.
- Phone through urgent results (this is ideal but not universal)
- Ensure new clinical colleagues have pathology codes set-up so results are not sent elsewhere.
- Review near misses/SEA.
- Advocate that the hospital communicates new cancer diagnoses in a timely fashion.
- Advocate that the hospital sends up-to-date diagnoses and treatment plans in a timely fashion.
- Ask the hospital to clarify follow-up plans if there are spurious (sometimes the clinician can be contacted on NHS.net).

During the **referral** process the GP should:
- Communicate to patient what to expect, and give them the cancer referral leaflet.
- Recommend using electronic methods to send cancer referrals (many sites now have dedicated email referral).
- Keep an electronic list of cancer referrals (this is made easier if referrals are coded).

During **follow-up of the patients**:
- Proactively chase non-attenders by calling or writing to them.
- Consider that vulnerable patients will require more flexibility (i.e.: elderly, illicit drug user, and alcohol dependent patients etc.).
- Ensure locums use electronic methods of relaying concern (i.e. tasks/alerts for patient with concerns).
- Administrative staff should also document their attempts to follow-up with the patient.

Strategies for **Locums** and when you are on leave:
- Give Locums a Locum Pack with information on how to refer and code.
- Ensure that the Locum uses the right pathology code so results come back to the regular doctor.
- Ensure results and/or letters are buddied up with another colleague if you are away.
- Ensure any concerns are relayed to a colleague before taking leave. This should be documented in notes.

**Proactive safety-netting** (tasks to be completed by various practice staff):
- QCancer risk assessment – run proactively
- Proactive searches for anaemia/thrombocytosis etc.
- Cancer reflection
- Cancer audit

### Table 6: Safety-netting codes which can be used

<table>
<thead>
<tr>
<th>Safety-netting code</th>
<th>Read code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Follow-up visit</td>
<td>9N7B</td>
</tr>
<tr>
<td>Follow-up appointment offered</td>
<td>n7M</td>
</tr>
<tr>
<td>Asked to come, investigate result</td>
<td>9N75</td>
</tr>
<tr>
<td>Follow-up</td>
<td>9c0H</td>
</tr>
<tr>
<td>Follow-up arranged</td>
<td>8H8</td>
</tr>
<tr>
<td>Patient asked to make an appointment</td>
<td>9N7C</td>
</tr>
<tr>
<td>Active monitoring</td>
<td>9Ok4</td>
</tr>
</tbody>
</table>

Table 6: Safety-netting codes which can be used
Figure 9: shows the Read codes for safety-netting and which top tier group they are filed under.
5. Medico-legal aspects to consider

QCancer can be used during a consultation with patients to calculate the absolute risk of a patient having a current as yet undiagnosed cancer, with separate risks for each type of cancer. It is a risk assessment tool and cannot diagnose cancer. The results of the calculation can then be shared with the patient and used to inform the decision to undertake further investigation or referral. Litigation concerns may be a barrier to utilisation of the calculator. I have made an enquiry with the Medical Defence Union, MDDUS and with the LMC. They have advised that transparency and cancer risk should be discussed with the patient. The extracts from MMDUS and the LMC are included here, consecutively:

“I think there might be criticism of a GP who was aware that a patient had cancer or potential cancer and was also aware that that patient had failed to engage with clinical input about the matter. You would need to be very careful to make it clear that you had taken steps to contact the patient and to make the patient aware of the potential risk they were running by not engaging with clinical care. Without this, I suspect that you would find yourself open to criticism and possibly legal action. As I say, the LMC may be able to advise you more accurately in this matter but I do urge you to be cautious.”

- MDDUS

“Risks to GPs include a civil action for negligence, referral to the regulator (GMC) for impaired fitness to practice by virtue of poor performance and action under the performers’ list regulations (suitability and/or efficiency). All of these may run in parallel and the criteria for action under these mechanisms are all different!

“Given that using the QCancer toolkit is prompted by symptoms, I think that failing to act if the risk were raised would certainly give rise to criticism, and have the potential for an action if the patient suffered harm as a result of failing to act in a timely way.

“Non-response to a screening initiative is slightly more problematic, but my advice would be that at the very least, this should be noted on an easily visible area of the patient record; in my practice, we would also check the patient’s address and send a reminder. There is a legal precedent for requiring action on patients who do not attend an appointment for considering further investigation of a potential cancer, but I am not aware (yet!) of any action taken for not following up a screening DNA. There is an argument to be made that any such follow-up is actually the responsibility of the screening organisation. The GMC’s Good Medical Practice does not address this area specifically.”

- Dr Tony Grewal
Medical Director, Londonwide LMCs

6. Proposal for future codes

Direct Testing should be coded in order to study the changes later. Examples of this would be: Direct to colonoscopy, direct to CT chest, direct to gastroscopy.

7. Reasons to improve GP practice

The reasons to improve GP practice are:

- These skills will benefit all chronic and acute diseases, not just cancer patients.
- These skills will help the GP to identify learning, better knowledge of patient symptom patterns, and opportunities for intervention in the patient’s behaviour.
- Better coding will help those diagnosed with cancer so they are not missed. It will also aid the patients care plans, and set a foundation for tailored care plans for patients who have survived a disease and require community follow-up or awareness.
- The research benefits could be immense because it could generate richer, more detailed and more accurate data. This data could be used to study and understand the patterns in disease and progression.
- Learning these skills will improve quality in the practice (a key area for GP appraisal and revalidation).
• It would improve financial measures. QOF and enhanced payments rely on accurate coding. Consequently payments are made based on the coded data. Savings may be made from less appropriate referrals because the patient’s histories are easier to follow and read.

8. Other systems

Since Read coding is a universal phenomenon, the remit of this document is for EMIS Web but the principle extends to other systems. Over the next few phases of the project I will review the compatibility of the principles here with Vision and System One.

9. Additional information

Presentations
Coding and safety-netting project presentation

Papers
Coding and safety-netting references
Coding and summarising protocol