

Online services: Data Quality Guidance for general practice

Executive summary

The quality of data in a patient's record can be assessed by the extent to which it meets the various purposes that the record is used for. For online services this means that it must be clear and unambiguous for the patient to understand, without displaying information that might be harmful to the patient or others or confidential information to other (third) parties. Poor data quality may be confusing and may mislead both patients and clinicians with a negative impact on the patient's health care and safety.

This guidance offers recommendations on how to record and maintain data that is fit for online services. The starting point is to think of data quality in terms of five headings: Complete, Accurate, Relevant, Accessible and Timely (CARAT).

There are specific aspects of data quality that affect particular parts of the record such as problems and diagnoses, other consultation codes, summarising data and laboratory results.

Definition

Data quality is an attribute of electronic patient records used as a measure of whether a record is fit for purpose. It can be assessed under five headings: completeness, accuracy, relevance, accessibility and timeliness (CARAT).

Background

The quality of the data in a patient's record can only be measured by the extent to which it meets each particular purpose for which it might be used (see Box 1). The [GMS contract](#) and [PMS arrangements](#) for 2015–16 require practices to promote and offer their patients online access to their detailed coded record in addition to the appointments and repeat prescribing services and summary data required in 2014-15. A good quality coded patient record must be fit for this new purpose.

This guidance explains how Patient Online has changed the criteria for a high quality electronic patient record and how practices may respond to this challenge.

Box 1: Data fit for purpose

The electronic patient record is created for many purposes, which include:

- record what happened in consultations, the opinion of the clinician and the plan agreed with the patient
- summarise important elements of the patient's health
- enable computerised decision support
- call and recall patients
- provide evidence for medico-legal purposes
- support practice administration
- demonstrate performance for payment purposes
- communicate with other clinicians, through shared record views
- enable clinical audit and research
- act as a resource for all secondary uses of the patient record.

The electronic patient record, even a view limited to coded data, may be complex and difficult for the patient to understand. It may contain data which may be potentially harmful or contain confidential data about a third person that the patient should not have access to. It may be in the patient's best interests for these sensitive data items to be hidden (or redacted) from online display. Unlike typical redaction, there is no indication in the online services view that the redacted data exists.

It is essential to screen each record before a patient is given online access to it (see Box 1). The patient may also want to hide certain data items from someone who has proxy access. Sensitive data should be redacted but if this is not possible it may be necessary to refuse to give the patient online access.

Box 2: Scenario 1

John Brown is an 18 year old student who has just started university. He registers with the university practice and hears that his friends are accessing their records online. He decides to request access as well.

His records have been received via GP2GP. The staff at the practice review his records and see that there is a coded record of Family History of Huntington's Chorea. It is not clear from the record whether John is aware of this history, so they elect to hide this code from online viewing until John has been seen and the doctor can ascertain whether he is aware of this history.

The practice may wish to establish a policy to minimise the recording of third party information, only doing so with the consent of the third party after they have been told that the patient may have access to their records.

In a good quality record any data that may be harmful to the patient should be hidden from display through online access. This may be an enduring decision or it may only be a temporary measure until the practice is able to discuss a new entry, such as a diagnosis like cancer, with the patient.

Good data quality that is clear, up-to-date, well-coded, organised and unambiguous is the most useful to patients and practices alike.

Poor data quality may be confusing and may mislead both patients and clinicians with a negative impact on the patient's health care and safety, e.g. it may lead the patient to request inactive repeat prescriptions left on the repeat list.

Once the practice offers online access to the detailed coded record, any patient may ask for access to their record. It is important to bear in mind, as you record data, that any patient may have access to their record in the future.

There are aspects of data quality and ways of maintaining and improving the data quality in a record that are specific to the computer system and terminology (Read V2, CTV3 or SNOMED CT). This guidance cannot give advice on how to use specific systems. It is better to use the training materials provided by the practice system supplier or the National User Group for detailed advice on how to achieve the principles of data quality discussed here.

Data Quality

Data quality in the electronic patient record has long been described by the acronym CARAT, standing for Complete, Accurate, Relevant, Accessible and Timely.

- **Complete** - A high quality record will include all the key data as coded entries that follow the usual guidelines on data quality (see [Good practice guidelines for general practice electronic patient records: guidance for GPs](#). 2011). With online access the patient may be able to help improve the record by identifying diagnoses or events that are missing. However there may be a conflict between a high quality record for the use of clinicians providing direct patient care and the need to redact potentially harmful or confidential third party data to prevent it being displayed online. This should not prevent sensitive data being recorded; it should either be redacted or if that is not possible, the patient should not be given access. It is essential that before online access is switched on for a patient, the data that the patient may see is checked and all sensitive data is redacted, at least until the practice can discuss the matter with the patient if it is appropriate.
- **Accurate** - A patient's record changes with time as problems come and go and diagnoses evolve. GP records have to represent uncertainty, so for example, where the diagnosis is still unclear, a working symptomatic problem code may be better than a diagnostic code. Remember that text qualifiers added to diagnostic codes may not be visible to the patient who may be misled as a result. Accurate medical terms are essential for clinical purposes but can be confusing for patients. Patients should be warned that they may not understand all the medical terms they will see in the record online when they register for Patient Online. There are several websites that will give them reliable information if they want to look things up e.g. [NHS Choices](#), [patient.info](#) and [Labtests online UK](#).
- **Relevant** - There may be data that is of particular relevance to online access that may not otherwise appear in the record, for example an active problem code to represent that the patient has online access to their records (codes: Registered for access to Patient Facing Services 9IW..; XabsS / Access to Patient Facing Services denied 9IX..; Xabsj / Registration for access to Patient Facing Service discontinued 8CT9 ; ZabsR). Bear in

mind the value of using codes that the patient can see instead of free text that they cannot see, for example in recording referrals, care plans, long term conditions or patient preferences.

- **Accessible** - There is no contractual requirement to give patients online access to free text or letters and reports and it is an onerous task to check for third party or harmful references. So any information recorded in free text may not be accessible to the patient. This may apply to free text comments attached to laboratory results and other codes. So do not rely on using parts of the record that the patient may not have access to to communicate with the patient.

Box 3: Using a test patient to demonstrate what a patient might see online

The interpretation and understanding of the coded record may depend on how the data is displayed online. To help patients understand their record, it is helpful to be familiar with how the record viewer that the patient is using configures their display.

If you can set up a test patient on your GP system, you can create and change the record to check how your system supplier configure their Patient Online display. Practice team members can log in and see how the different configuration settings available with the system influence what the patients can see and allow practices to explore the options. It may also be used to demonstrate to patients what they will be able to see and what it means.

It should be noted that different patient facing services providers may display the same information in different ways. Patients need to be aware of this possibility too.

- **Timely** - This normally refers to recording consultations at the time of the event, rather than at a later time. For online services it is helpful to patients if their GP views, comments and files investigation reports as soon as possible after the results arrive in the practice.

Data fit for Patient Online

To help patients make good use of online access you may want to give them some background information about their records when they register. Patients are often unaware of exactly what is in their records or what will be available to them. You may want to record that you have given this advice or include it in patient information leaflets at the time of registration for online access.

Nevertheless patients may misunderstand their records, especially if the data quality is poor. You may wish to advise them to contact the practice if they see anything that they do not recognise or understand, particularly if it causes them concern. Some Read codes are ambiguous and the patient may think that they represent something that they do not recognise or is more serious than they thought (e.g. arthralgia of the lower limb, or cardiac syndrome X).

Difficulties may arise if a diagnosis or suspected diagnosis code is added to the record when the diagnosis is uncertain and may later prove to be incorrect, unless it has been discussed with the patient. A code for suspected cancer, for example, may be frightening if nobody has explained the possibility. It may be best to redact such entries until the uncertainty has been cleared up or the possibilities have been discussed with the patient.

Patients may identify errors in the record and ask the practice to correct them. This can contribute to their healthcare. There may be a missing operation or it may bring to light a misunderstanding over medication dosage. The practice should respond positively to the feedback.

Patients may disagree with something in the record and ask for it to be removed, but it is up to the practice to decide whether or not to agree to the patient's request. If the decision is not to change the record, the practice should carefully explain the reasons to the patient. Patients may react strongly to something they find challenging or stigmatising. NICE has produced [guidance](#) on how to manage challenging or threatening behaviour from patients. There is advice below about how to improve the data quality for online access.

The practice has a duty of confidentiality to anyone who shares patient information with any of the practice team, whether or not it is recorded in the patient record.

Creating good quality records for online access

The principles of using codes to create high quality electronic patient records are described elsewhere (see [Good practice guidelines for general practice electronic patient records: guidance for GPs](#) and [PRIMIS website](#)). They apply to online access as well but the additional considerations described above are also relevant to creating records. Although existing records are often best left unedited unless the practice system allows it to be done without hiding or deleting the original code that was chosen when the record was created, there are some principles that it may be helpful to support online access to the detailed care record.

Diagnosis and problem codes - there is good practice advice available for choosing codes for all GP systems. Choosing accurate and unambiguous codes is particularly important if the patient will see them, e.g. terms such as “depressed” for emotional upset or “renal failure” for CKD 3 may be worrying if the patient is not expecting to find them in the record.

“History of” codes are ambiguous. “H/O TIA” may mean that the patient has described a history that sounds like a transient ischaemic attack, that they say they had a TIA in the past or that they did have TIA but it is not clear when. The patient may interpret the code in any of these ways.

Synonyms can cause a problem. These are codes that are appended to normal Read codes that usually, but do not always, mean the same thing. The linked real Read code may be displayed online rather than the synonym causing confusion (e.g. postnatal depression is a synonym linked to neurotic depression, reactive type which might be displayed to the patient instead of the code on the GP record). It is best to avoid synonyms for significant or major problems.

Whenever possible it is better to use the same code each time a patient presents with the same problem so that it is clear whether the patient has had one or several episodes of the same condition or many. That may mean combining or evolving problem codes if your GP system has that functionality.

When a diagnosis changes, do not simply add the new diagnosis, but where the system functionality allows, link the previous code for the problem to the new one, to avoid confusion for the patient. Again, depending upon system functionality, it may be possible to very carefully delete erroneous entries without changing the meaning of previously recorded data or consultation records. The working diagnosis when a consultation record is created must be preserved in case it is needed as medico-legal evidence. An example is where deleted problem titles remain visible along with a replacement as consultation headers. This tends to be a system-specific function and if in doubt it is best to check the guidance provided by the practice system supplier or National User Group.

To improve accessibility to the patient it is helpful to keep the active problem list up to date, transferring codes for problems that are concluded or dormant to the past or inactive list.

Other codes in the consultation record - Whenever you would like the patient to be able to see data online, use codes rather than free text (which won't necessarily be visible). This is particularly relevant when recording data items about a patient's long-term condition as it will help them monitor that condition. Practices are already used to coding data for the Quality and Outcomes Framework. Using online access to help patients or their carers to manage their long term conditions or palliative care is another reason for coding data that might otherwise be recorded in free text. This includes follow up and referral plans and actions.

Summarising new patient records - Data that patients find helpful to check online include allergies and adverse reactions, vaccinations and immunisations and screening procedures such as the last cervical smear or mammogram, even if the results were normal. If you would not normally code the data when new patient records are summarised consider reviewing the practice summarising protocol, if you have one, and add items that patients would like to be able to see.

Data entry from hospital and other reports - Similarly there are data items in these reports that may not normally be coded in the record but they can be helpful to the patient, for example normal major investigations such as endoscopies or referrals.

Maintaining data quality

Diagnosis and problem codes - There is a natural tendency for patients problem and diagnosis lists to grow for a variety of reasons. Important entries may be duplicated or different codes used for the same problem. Entries that are not really problems, such as minor procedures and administrative data, may appear on the list. Problems that are long since over and of little current relevance may litter the active problem list. This looks untidy and it is difficult for the patient to understand a poor quality problem list. So it is worth finding a moment or two to maintain the problem list. How much you can achieve and how you do it depends upon which GP system you use but the principle actions are to:

- Combine multiple code entries for one problem or one episode of a problem, leaving the best code and most accurate onset date in the visible record
- Delete any incorrect codes in a secure manner so that they are not removed from the record altogether
- Inactivate problems that are no longer active
- Activate problems that are on the past or inactive list if they are still active; they may still be the reason for an active repeat prescription item.

All codes - remain vigilant for the appearance of codes that may be harmful to the patient or refer to third party information. Consider redacting them so that they are not visible to the patient. Discuss the item with the patient at the next opportunity if it is appropriate.

Medication

Make sure that repeat prescription lists are up to date. Consider removing items that have not been issued for more than six months (with the well known exceptions such as summer antihistamines and occasionally used inhalers and topical treatment). Check that dose instructions are up to date.

Practice Training

Once patients have online access to their detailed coded record, the impact of data quality becomes a new responsibility for the practice. Not only is this relevant for patients who have online access, it should be borne in mind that any patient may sign up for online access in the future. It should be included in practice training and protocols on data quality and information governance for all staff who contribute to the patient records.

Summary

High quality data is data that is fit for all the purposes for which it will be used. Online access to the detailed coded record is a new purpose for the record. This affects everyone in the practice who contributes to the record and the quality of the record of every patient in the practice. This paper has explained how online access has changed the concept of data quality and how practices may adapt their data recording and maintenance for the purpose of online access.

Further information and resources

- [GMS contract change for 2015/16](#)
- [PMS arrangements for 2015–16](#)
- [Good practice guidelines for general practice electronic patient records: guidance for GPs.](#)
- [NHS Choices](#)
- [patient.info](#)
- [Labtests online UK](#)
- [NICE guidance Violence and aggression: short-term management in mental health, health and community settings](#)
- [PRIMIS website](#)