DATA QUALITY

Since 31 March 2016 English practices have been contractually required to promote and offer online access to “all information from the patient’s medical record which is held in coded form” as well as the usual transactional services. The requirement has not changed since then. By June 2018 almost 6% of patients in England had online record access.

There is also a non-contractual requirement for practices “to provide patients with online access to clinical correspondence such as discharge summaries, outpatient appointment letters, and referral letters [from a chosen prospective date] unless it may cause harm to the patient or contains references to third parties.” There is no requirement to offer access to consultation free text and word-processed care plans but all GP systems are capable of this.

A good quality patient record must be fit for these new purposes. It is not always clear which patients have online record access and it is impossible to know who might have access next month. It makes sense for everyone in the practice who is recording information in the patient record to bear this in mind at all times. This guidance is intended to offer guidance to clinicians about how they should respond to this challenge.

Box 1: Good data quality is data fit for purpose
The electronic patient record is created for many purposes, which include to:
- 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.

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

Complete - In a high quality record, all the key data about a patient’s health will be coded (see the Good practice guidelines for general practice electronic patient records: guidance for GPs. 2011). Patients with record access may offer diagnoses, allergies, vaccinations, operations or events that they see are missing.

Accurate - A patient’s record changes with time as problems occur and become inactive and as working symptom-based problems acquire a formal diagnosis. GP records must represent clinical uncertainty; coding an uncertain diagnosis may be misleading. Text qualifiers that record uncertainty may not be visible to the patient, or other clinicians using shared records. When different codes are used for one condition it may appear as though there have been several episodes of, for example, stroke or cholecystectomy. Some diagnosis codes are ambiguous and are best avoided. Patients should be warned when they apply that they may not understand all the medical terms in their record (see Health Literacy below).

Relevant - There may be data that you would normally not code, that would be of particular interest to the patient if they could see it in the
detailed coded record. Examples include an active problem code to represent that the patient has online access to their records or care plan details.

**Accessible** – Patients do find extended access to consultation notes and clinical correspondence helpful, especially if they have multimorbidity and complex healthcare. A practice standard for free text entries in consultation notes is useful; avoid abbreviations, euphemisms and medical jargon that may mislead or confuse the patient. Record the level of access that each patient has and the reasons for the decision. Depending upon the GP system functionality it may be possible to check what the patient can see online (see Box 2).

**Timely** - This normally refers to recording consultations at the time of the event, rather than at sometime later. 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. Patients should also be encouraged to view their record if it is to be used as a means of communication between the practice and the patient, e.g. about laboratory results or hospital letters.

**Coding data for online access**
The principles of using codes to create high quality electronic patient records described elsewhere (see the [Good Practice Guidelines for GP electronic patient records - Version 4](#) (2011) can be applied to online access).

**Diagnosis and problem codes** - Although the GP systems manage diagnosis and problem codes differently there are principles that apply to all systems and are important to patients using online record access.

It is very important to pick accurate and unambiguous codes. 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. Some codes are particularly ambiguous. “History of” codes are good examples. “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 codes that usually, but do not always, mean the same thing. The linked real code may be displayed online rather than the synonym causing confusion. 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 operation. That may mean combining or evolving previously-recorded problem codes with the current code that you prefer, if your GP system has that functionality. So, when a diagnosis changes, add the new diagnosis and link the previous code for the problem to the new one, to avoid confusion for the patient.

If your system has this function it may be possible to carefully delete previous erroneous entries without changing the meaning of old data or consultation records. It is essential to preserve the record of the working diagnosis when a consultation record was created, not least because it may be important medico-legal evidence.

For clarity for 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** - To enable the patient to see data online, use codes rather than free text to record it (unless they have full access to consultation notes). For long-term conditions it will help patients and their carers manage their
health or palliative care and improve their health literacy and ability to share in decisions about their health. There is more information about this in the guidance on clinical scenarios in the toolkit.

**Free text** – Bear in mind that although what you write in the notes is a means of communication with the patient, you cannot rely on it entirely unless you are confident the patient will check their record online in a timely manner. If you want to use free text added to something like test results to communicate with the patient, you must warn them to check the record when the results are due back and backup your communication with another means such as an SMS text, phone call or letter, especially if the patient does not take the action you recommended, such as making a follow-up appointment. Avoid using acronyms, abbreviations and medical jargon that the patient may misunderstand. Remember that shortcuts that are understood by colleagues may not be intelligible to patients (“no neck stiffness” makes it clear to a health professional that meningitis was considered and excluded but that may not be clear to patients).

**Summarising new patient records and reports**
- Data that patients find helpful to check online should be part of the summarising requirement for new records or reports arriving in the practice. Allergies, adverse reactions, vaccinations and immunisations, and screening and investigation procedures such as the last cervical smear or an endoscopy are important to patients, even if the results were normal. Consider reviewing the practice summarising protocol with Patient Online in mind. There is more information about coding health data for Patient Online record access in the guidance on the Detailed Coded Record in the toolkit.

**Patient concerns about their records**
When patients sign up for record access, they are often unaware of what is actually in their records or what they will be able to see. To help them make good use of their access, you may be able to help them by explaining what is in their records and what it means to them personally. This is most helpful for people with complex multi-morbidity or a poor understanding of their health. 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.

Patients should feel confident that they can report questions about their record to the practice. There may be things they do not understand in the record, omissions, mistakes, or something that they find upsetting or with which they disagree. Their comments should be discussed openly and honestly, and changes made to the record if appropriate. The practice is under no obligation to change the record unless you think that the change is correct. If you refuse to make a change at the request of a patient, it is reasonable to add a note that the patient asked for the entry to be changed or added.

Patients may still misunderstand their records, especially if the data is ambiguous. 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.

Patients are likely to be worried if they see a new diagnosis or suspected diagnosis that they are unaware of. Clinical correspondence may contain possible diagnoses without being clear whether it has been discussed with the patient. It may be best to redact such entries, particularly if the diagnosis has serious implications, 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. There may be a missing operation or a misunderstanding over medication dosage. The practice should respond positively to the feedback and update the record if it is appropriate.

Patients may react strongly to something they find challenging or stigmatising. NICE offers guidance on how to manage violent of aggressive patients (Guideline NG10).

There is more information about the right of patients under the General Data Protection Regulation 2018 to have personal data rectified.

**Harmful data**
GP records may contain information that patients find challenging or upsetting, particularly if they do not expect to come across it online or if it has not been clearly explained to them before they come across it. It may also be dangerous for patients if a third party is able to discover information relating to abuse or other matters in the record.

Examples include an entry about substance misuse; or about suspected or actual abuse,
violence or coercive behaviour towards the patient or a third party.

Someone who is abusing the patient may be triggered or enabled to increase the abuse if they gain access to sensitive data about the patient such as family planning information or any indication that the abuse is suspected by the practice. Communication from domestic violence agencies and multi-agency risk assessment conferences (MARACs) to general practice will lead to highly sensitive letters being filed in the GP practice record. It is important to redact any entries, which might alert an abuser to the possibility that their activities are under suspicion.

Patients may research an entry that they do not understand, and come to the wrong conclusion about what it says about them. It is best to discuss the meaning of entries with the patient before they have online access, redacting data that may be sensitive if that is not possible (see below).

It is essential to check the record for potentially harmful data whenever a patient applies for record access before access is switched on. It can be time consuming. There is commercial software that will search for a standard set of sensitive codes and free text words in consultation notes and scanned documents. It may speed up the process but cannot be relied upon to find all the data that might be harm an individual patient. The sensitivity of a specific data item depends upon the circumstances of the patient.

Patients or their proxies may ask for entries to be altered or removed if they disagree with them or find them upsetting or offensive: in some cases, the patient may be verbally or physically abusive, or try to resort to legal measures to have their requested changes effected. However, all health professionals have a right (and a duty) to make complete records of facts and their professional opinions about their patients’ health, indicating clearly which are facts and which are opinions. Entries that may upset patients may be redacted to protect the safety of members of staff or third parties, preferably temporarily until the entry can be discussed with the patient.

**Recording third-party data**

This is data received from a third party or data about a third party (e.g. agreed recorded family history data). It may appear in coded information, consultation notes, or scanned documents. It may be information recorded by mistake in the wrong patient’s record. Disclosure may be a breach of data protection law and may result in harm or distress to the patient or breach the confidentiality of the third party.

Before recording anything about a third party in a patient’s record, including identifying the source of information about the patient provided by a third party, you should discuss with them the possibility that the patient will see the information if they have access to their records. There are four steps that you can take if you decide to record the data:

- Ensure that the third party understands that the patient may be able to infer the source of the information
- Ensure that the third party is prepared to bear that risk or to have their identity explicitly recorded.
- Obtain and record the consent of the third party for the patient to have access to the information before recording the information
- Redact the information so that the patient cannot see it online, but it may still be included in a paper printout of the patient’s record and available to the patient through a subject access request under the Data Protection Act 2018.

The third party may decide to withhold the information or make it clear that they do not wish it to appear on the record of the patient.

**Redaction of sensitive data**

Sometimes the record will contain sensitive data, which it may not be in the patient’s best interests to see. This may be because it may cause them distress or put them at risk of harm (e.g. data relating to personal abuse). The data may have been entered in the record for a good reason and should not be deleted, but every GP system as the ability to hide specific data items from view via Patient Online. This is called redaction. The data is not deleted from the record or hidden from practice team members, so it remains available for use in patient care in the practice, but there is no indication through online record access the redacted data exists. There is information about sensitive data, including confidential third-party data that should be redacted in Appendix 1.

Before record access is switched on it is necessary to ensure that the clinical record is fit to be shared with the patient. The process is called “clinical
assurance”. It can be a time-consuming process. There is commercial software that can speed up the process by searching the record, including scanned documents, for potentially sensitive codes and text. A trained medical summariser can also help to check the records and redact clearly sensitive data but the final decision on redaction and refusal or restriction of record access if sensitive data cannot be redacted should lie with a senior clinician. There is more information about the clinical assurance process in Appendix 2.

Redaction of potentially sensitive data in every patient’s record is important, not just patients with Patient Online record access or those who may ask for record access in the future. It also helps avoid distress for the patient if health professional in another organisation sharing access to their data, sees sensitive data they are not aware of and discusses it with them. Redaction automatically prevents the data being visible when access is shared for direct care with other health professionals.

Redaction may be reversed after discussion with the patient. An abnormal result may be redacted until there is an opportunity to explain what it means. Sometimes redaction has to be permanent, particularly for confidential third-party data.

If there is sensitive data in the record that cannot be redacted, it may be necessary to restrict, refuse or withdraw Patient Online access.

There is more information about clinical assurance in the Online Record Access - getting started guidance and on the management of sensitive data in the guidance on Safe Patient Online Record Access in the toolkit.

Box 3: Clinical Scenario
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.

Maintaining data quality

Diagnosis and problem codes - There is a natural tendency for patients’ problem and diagnosis lists to grow and important entries may be duplicated, or different codes used for the same problem. Problems that are inactive and of little current relevance may litter the active problem list. Entries that are not really problems, such as minor procedures and illnesses or administrative data, may appear on the list. It is difficult for patient and clinicians to use a poor-quality problem list, so it is worth finding a moment or two to curate the problem list. How much you can achieve and how you do it depends upon which GP system you use but the principle actions remain the same:

- 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 have become harmful to the patient or refer to third-party information and redact them. Consider discussing the item with the patient at the next opportunity if it is appropriate.

Medication - Make sure that repeat prescription lists are up to date, removing items that have not been issued for more than six months (with the well-known exceptions such as summer antihistamines and infrequently used inhalers and topical treatments). Check that dose instructions are up to date and written in plain English.

Health Literacy

It can be time consuming to help patients improve their health literacy. Using tried and trusted techniques such as “chunk and check” and “teach back” to explain important terms in the record can help. Patients can use their detailed coded record as a list of terms to learn about and understand their condition. By encouraging patients to engage with their own health record, they are more likely to become inquisitive and engaged with their diagnoses, investigations and treatments that they identify within the record itself.
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 patient’s record is a new purpose for the record. This affects everyone in the practice who contributes to the record. This guidance 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 reading

GP Contractual requirements in England, links from NHS England website (https://www.england.nhs.uk/gp-online-services/about-the-prog/gp-practices/)


NHS Digital, SNOEMD Implementation in Primary Care has resources to help GP practices transfer from Read codes to SNOMED CT (https://hscic.kahootz.com/connect.ti/t_c_home/view?objectld=299987&exp=e1)

PRIMIS, University of Nottingham, Clinical and data quality assessment tools, accessed on 20 October (https://www.nottingham.ac.uk/primis/tools-audits/tools-audits/pdq/pdq.aspx)

www.nhs.uk, Information from the NHS about health for patients (https://www.nhs.uk)

Patient, Information from EMIS Health about health for patients (https://patient.info/about-us)

Labtests Online UK from the Association for Clinical Biochemistry and Laboratory Medicine, Information for patients on laboratory tests (https://labtestsonline.org.uk)

Niche Health UK, iGPR, an example of a screening tool for third party and sensitive information contained within the clinical codes, free text and attachments of a patient’s GP record (http://www.igpr.co.uk)

(All webpages accessed on 20 October 2018)
Appendix 1

Summary of when record access may be detrimental to the patient

1. **Sensitive data** - A patient may be upset or angered by something they find in their GP record. They may misunderstand the significance of something and believe a serious illness has been kept from them or a diagnosis has been made that they disagree with. Careful discussion with the patient, focusing on the meaning of the data and the clinical reasons recording the data will often resolve the issue.

2. **Third-party data** - There may be confidential data in the patient’s record that was provided by or is about a third party, to whom the practice owes a duty of confidentiality. If someone’s privacy has been breached by record access, they must be informed as soon as possible.

3. **Poor-quality records** - Especially omissions or mistakes, may be misleading to healthcare staff and lead to poor care. Be prepared to add substantiated past medical history to the patient’s record.

4. **Newly-registered patients** - If their old practice record was transferred by GP2GP redaction settings may be removed. They may not be recorded at all in paper printouts. It may be some weeks before the record can be summarised and clinically assured for Patient Online. Online access should not be switched on until the new record has been summarised and checked. Warn patients that if their old practice used a different GP clinical system, the record may look very different.

5. **Coercion** - A patient may be at risk from one or more malign third parties. A child or a vulnerable adult may be coerced by someone who may want access to the patient’s record to control their access to healthcare. This is perhaps the most important risk of using Patient Online. New applicants for online access should always be asked questions that probe whether the patient is under pressure to open a Patient Online account unwillingly. Check the record for evidence of previous domestic violence or abuse. This is not only relevant when a patient applies for online access, it is important to remain vigilant for evidence of abuse or coercion at all times. There is more advice on how to recognise and prevent this form of abuse in the guidance on Coercion in the toolkit.

6. **Data security** - If the patient is unable to understand how to keep their online access secure, they may be at particular risk of a third party gaining access to their record. The Good Things Foundation coordinate a network of 5,000 local learning centres where patients can learn to use computers and the internet safely ([https://www.goodthingsfoundation.org](https://www.goodthingsfoundation.org)).
Appendix 2
Outline practice policy on checking the records for online access.

A practice policy on checking patients’ records before they are given online access to their record should be written to establish meet the practice’s requirements. The following are worth considering for inclusion.

1. **What is the purpose of checking the record?** To ensure the clarity completeness, accuracy and redaction of all sensitive data. Remember that the data may look different in the Patient Online app or webpage from the record in the practice system.

2. **Which parts of the record should be checked?** All of the record that the patient will be able to see should be checked. If access to consultation notes and clinical correspondence is being considered, it may reduce the risk of missing sensitive data in a large record with many scanned documents and save time by restricting access to new scanned documents or consultation notes made after Patient Online access is switched on. This is called ‘prospective access’.

3. **What should be redacted?** Data that may lead to harm to the patient and confidential data that relates to a third party. Data that may relate to safeguarding issues should always be redacted. The sensitivity of the data is strongly influenced by the circumstances and views of the patient. The assessment of what should be redacted must be made in the individual patient’s best interests. Clinicians must use their professional judgment and knowledge of the individual in deciding whether data should be redacted. There is more information about these problems in the guidance on Safe Patient Online Record Access in the toolkit.

4. **Every record must be checked** before a patient or a proxy is allowed access to the record online. For proxy access, ensure that the patient has seen the record and is happy to allow the proxy access, possibly after redaction of some data.

5. **Who should check the record?** This could be a task for the clinician who knows the patient best, another experienced clinician, or the Patient Online clinical lead. It can be done by well-trained non-clinical staff. Agree when to escalate decisions about redacting an item or refusing or restricting the patient’s online access.

6. **How many records can be checked?** Record checks are time consuming, even with using software to screen the record before a manual check. It may help to limit the number of records checked each month. It helps to be able to warn patients how long they may have to wait when they apply for record access.

7. **When should online record access be refused?** If there is sensitive data that cannot be redacted, it may be best to refuse of limit record access. Consider discussing the decision with an experienced clinician such as the practice Patient Online or Safeguarding Leads. It may be possible to allow access after a careful discussion with the patient.

8. **Should the patient be told that data has been redacted?** The reasons for redaction, for refusing or limiting online access should, where possible, be discussed fully and openly with the patient. The goal is to be able to allow the patient online access whenever possible. The reasons for redaction, for refusing or limiting online access should always be recorded in the patient’s records (in an entry which should also be redacted).

9. **In future,** practices should feel confident to record whatever is needed, fully and honestly, distinguishing carefully between facts and opinions, and then immediately redact entries, which they feel are currently unsuitable for online viewing.