

GP Online Services Guidance

*Data quality for record access*

Contents

1. Introduction 1
2. Good quality records for online access 2
3. Patient concerns about their records 6
4. Maintaining data quality 6
5. Health literacy 7
6. Practice training 8
7. Summary 8

Introduction

From 31 March 2016 English practices have been contractually required to promote and offer online access “all information from the patient's medical record which is held in coded form” as well as the usual transactional services. The 2019-2020 GMS contact included the following commitment (5.10(ii))

*“All patients will have* ***online access to their full record****, including the ability to add their own information, as the default position from April 2020, with new registrants having full online access to prospective data from April 2019, subject to existing safeguards for vulnerable groups and third-party confidentiality and system functionality.”*

In 2022 NHS England introduced automatic record access for everyone who had access to at least one GP Online Service via a patient facing service app or web portal such as the NHS App, Patient Access, Airmid or Evergreen.

By June 2022, over 47% of patients in England had access to at least one GP Online Service and 13% had detailed coded record access. More patients use the NHS App to view their COVID vaccination results.

A good quality patient record must be ready for patients to view the record. With automatic record access practices will have lose the opportunity to review the record, improve the data quality or hide potentially harmful data from patients that is available when patients apply for record access.

Unless practices maintain good quality records at all times and communicate well with patients about online record access, patients could potentially come to harm. The legal responsibility to ensure that patients do not come to harm in this way lies with the practice. This will require a response from everyone in the practice team who is responsible for creating or managing records, including locums and trainees.

Every item of information, every laboratory report, document, SNOMED term and free text entered in the record of every patient at any time has to be fit to share with the patient.

This guidance is intended to help practice teams respond to this challenge. It may be read in conjunction with the guidance on “Managing Potentially Harmful Information” in the Toolkit

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
* communicate with other clinicians, through shared record views, for direct care
* provide evidence for medico-legal purposes
* support practice administration
* demonstrate performance for payment purposes
* enable clinical audit and research
* act as a resource for all secondary uses of the patient record.

Good quality records for online access

Clinical records that are accurate, unambiguous and well organised support patients and clinicians alike. Inaccurate, ambiguous and badly curated data can be confusing and may mislead both patients and clinicians and potentially have a negative impact on the patient’s healthcare and safety.

Some information in the record may cause harm to the patient or others or disclose confidential information relating to a third-party. This may be essential information to record for good clinical care but it should be hidden from view by the patient with online access. This is called redaction. This should not prevent clinicians providing direct care to the patient from being able to see the information but systems should display an indicator that data has been redacted so that nobody directly discusses the information with the patient while providing care.

Data quality in the electronic patient record has long been 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. 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; using a diagnosis code when the diagnosis is uncertain or has not been confirmed may be misleading. Using multiple different codes for one event such as an injury or major operation, may give the appearance that there have been several different events in the patient’s history. Some diagnosis codes are ambiguous and are best avoided, such as “depressed” for unhappy or “renal failure” for CKD stage 3. Patients may need help to understand medical terms in their record.
* **Relevant** - There may be data that the practice would normally not code, that would be of particular interest to the patient if they could see it in the detailed coded record. Over time a patient’s health may change or the practice’s understanding of a diagnosis may change as investigations and referrals are completed. It is important to maintain the accuracy of the record by deprecating previous inaccurate codes in whatever way your practice clinical system allows you to do. A practice standard for free text entries in consultation notes is useful; avoid abbreviations, euphemisms, unsupported opinions and medical jargon that may mislead or confuse the patient.
* **Accessible** – Patients find access to consultation notes and clinical correspondence helpful, especially if they have multimorbidity and complex healthcare needs, but records can then fill many pages of the screen for patients and the practice. Coding important information makes it more accessible. Record the level of access that each patient has and the reasons for the decision. Depending upon the GP IT/Clinical systems functionality it may be possible to check what the patient can see online (see Box 2).
* **Timely** - This refers to recording consultations at the time of the event, rather than at some time later and ensuring that when entering past events, they are dated as accurately as possible. This is especially important with automatic online record access where patients only have access from a defined date: either the date that automatic record access is launched or when they joined the practice if that date was later. Past information that may be harmful will not appear in the patients’ online view of the record if it is clearly dated before automatic access was switched on. It also helps to avoid confusing the patient with inaccurate dates. Patients who have online record access find it helpful if their GP reviews, comments and files investigation reports, and then informs them of any unexpected news as soon as possible after the results arrive in the practice.

However, it is best to avoid using auto-file systems for laboratory results if your practice system offers the functionality. Auto-filed information may become available to the patient before there has been a chance to see if it needs to be hidden from view.

Box 2 explains how to set up a practice test patient with a valid NHS number for you to test how your practice system manages online access with auto-filing.

Box 2: 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 good to be familiar with how the record looks online. It is also helpful to become familiar with how reliably the practice computer system is able to hide all data that is flagged “hide from online view” without it being clear that something has been hidden, an expected consultation or laboratory result for example.

To do this you can **set up a test patient** in your clinical system with a valid NHS number and a corresponding access in a patient facing services (PFS) app. This will give you confidence about whether you can safely hide harmful or confidential third-party data from online view.

Note: an existing test patient without a valid NHS number cannot be linked to a PFS app, a valid number from NHS Digital is essential.

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.

Ref Guidance on “setting up a test patient and NHS number” in the Toolkit and NHS Digital advice on how to set one up - https://digital.nhs.uk/services/nhs-app/nhs-app-guidance-for-gp-practices/set-up-a-test-patient (accessed 10 July 2022)

**“History of …” codes** - These are codes such as “*History of Domestic Violence*” need to be used with care. They are ambiguous (do they mean that the patient has a certain history of domestic violence in the past or that they are currently reporting domestic violence or that they are a past perpetrator of domestic violence) but, most importantly, it is tempting to use them with a current date when they refer to events in the past. This is misleading and it may expose past harmful data to the patient or a third party in the online record unnecessarily.

**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 as the sole means of communication unless you are confident the patient will check their record online in a timely manner. If the practice would prefer 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. It may be wise to back up your communication with another means such as an SMS text, phone call or letter, especially if the information is urgent or patient does not take the action you recommended.

Avoid using acronyms, abbreviations, euphemisms, medical jargon or anything the patient may be upset by in the free text. Remember that shortcuts that are understood by colleagues may not be intelligible to patients (the meaning of “no neck stiffness” is clear to a health professional who immediately knows that meningitis has been excluded but that may not be clear to patients).

Be careful in recording confidential information received from a third-party or about a third-party that the patient has no right to have access to. If it becomes visible to the patient online, it may cause harm or distress to the patient or the third-party or breach the confidentiality of the third-party. There are four steps that the practice can take to record the information:

1. Check if the third party is willing to have their identity explicitly recorded.
2. Ensure that the third-party understands and accepts that the patient may be able to infer the source of the information and the third-party referred to.
3. Obtain and record the consent of the third-party for the patient to have access to the information before recording the information.
4. If necessary, hide confidential information so that the patient cannot see it online.

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

**Summarising new patient records and reports** - Information that patients find helpful to find online should be part of the summarising requirement for new records or reports arriving in the practice. Allergies, adverse reactions, vaccinations and immunisations, 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 GP Online Services record access in mind.

Ref: For more information about how to maintain accurate and useful coded record to support collaborative person centred care with patients’ online record access in the guidance on clinical scenarios in the Toolkit. These are diabetes, inflammatory arthritis, dementia, end of life care and mental health disease.

Ref: For more information about hiding potentially harmful information from view through patients’ online access in the guidance on “Managing Potentially Harmful Information” in the Toolkit.

Ref: For information about services to improve data quality for clinical care PRIMIS here - https://www.nottingham.ac.uk/primis/qi-services/qi-services.aspx (accessed 10 August 2022)

Ref: The Caldicott Review, Information to Share or Not to Share, 2013. section 3.9 has advice on managing third party data, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/192572/2900774\_InfoGovernance\_accv2.pdf (accessed 11 August 2022)

Patients’ 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, the practice may be able to help them by explaining what is in their records and what it means to them personally.

Ref: [Abbreviations you may find in your health records - NHS account help and support - NHS (](https://www.nhs.uk/nhs-app/nhs-app-help-and-support/health-records-in-the-nhs-app/abbreviations-commonly-found-in-medical-records/)www.nhs.uk) is a helpful guide to abbreviations and referenced in other sources of guidance.

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. It is important to document the patient’s request and the practice’s response. The practice might ask them to put the request in writing.

The practice is under no obligation to change the record unless the practice thinks that the requested change is correct. If the practice declines to make a change request by a patient, it is a good idea to add a note that the patient asked for the entry to be changed or added and the reason the change was not made.

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 hide 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 react strongly to something they find challenging or stigmatising. NICE offers guidance on how to manage violent or 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 at https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/individual-rights/right-to-rectification/ (accessed on 11 August 2022)

Maintaining data quality

**Safeguarding risks** – General practice should be vigilant to identify evidence that a patient may be at a safeguarding risk. It is worth noting that a patient's experience and risk of abuse can fluctuate over a lifetime, so practices will always need to be alert to historical, current and emerging safeguarding concerns.

Primary Care records hold a vast, and increasing, amount of safeguarding-relevant information. This includes personal disclosures by patients of their own experience of abuse (of which there are many different types) as well as information about perpetrators of abuse and criminal records. There is also a significant amount of highly sensitive information from other organisations such as the Police, Social Care and education.

The records also contain potentially harmful information about issues such as mental health, contraception, sexual health including HIV (human immunodeficiency virus), pregnancy/terminations and gender identity which could be dangerous in the hands of an abuser who might coerce the patient into giving them access to their online record.

There is further guidance on safeguarding risks for vulnerable groups in the Clinical Safety section of the Toolkit.

Ref: Advice for GPs on asking about and discussing safeguarding risk from SafeLives - https://safelives.org.uk/sites/default/files/resources/Pathfinder%20GP%20practice%20briefing.pdf (accessed on 11 August 2022)

**Diagnosis and problem summaries** -There is a natural tendency for patients' problems 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 significant problems, such as minor procedures and illnesses or administrative data, may appear on the list. It is difficult for patients 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 can be achieved and how this is done depends upon which GP clinical IT system you are using but the principal 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 or update 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 problem and operation lists to learn about and understand their conditions. By encouraging patients to engage with their own health record, you empower them to become inquisitive and engaged with the diagnoses, investigations and treatments that they see in their record.

Ref: Reliable sources of information about health information for patients include

NHS.UK https://www.nhs.uk/conditions/ (accessed on 11 August 2022)

Patient Information from EMIS Health about health for patients - https://patient.info/about-us (accessed on 11 August 2022)

Labtests Online UK from the Association for Clinical Biochemistry and Laboratory Medicine, Information for patients on laboratory tests - https://labtestsonline.org.uk (accessed on 11 August 2022)

Practice Training

When patients have GP Online Services access to their health record, the impact of data quality on them is the new responsibility for the practice. Bear 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 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 document has aimed to explain how GP Online Services access has changed the concept of data quality and how practices may adapt their data recording and maintenance for the purpose of online access.