Online services: Detailed Coded Record
Guidance for general practice

Executive Summary
The 2015-2016 GMS contract and PMS agreement require practices to promote and offer their registered patients online access to all coded data in their GP records, referred to as their detailed coded record, by April 2016.

NHS England specification in the Patient Online support and resources guide is:

- Demographic data
- Investigation results including numerical values and normal ranges
- Problems/diagnoses
- Procedure codes (medical and surgical) and codes in consultations (symptoms and signs)
- Biological values (BP and PEFR)
- Immunisations
- Medication
- Allergies and adverse reactions
- Codes showing referrals made or letters received
- Other codes (ethnicity, QOF)

Generally patients want to use the detailed care record to:

- Find out what the GP record holds
- Identify omissions and mistakes in the record
- Check investigation results
- Review the recorded problems and diagnoses
- Monitor the progress on long term conditions
- Check their immunisation status

Patients should not use the coded data that they can see online to complete insurance, employment or legal documents.
Practices have a responsibility to ensure patients do not see harmful data or confidential information about third parties when they access their record. Free text attached to Read codes may be made available online by GP system suppliers as a configurable setting. This can be helpful to patients but, as with the coded data, may include harmful, misleading or third party information. Whenever a patient registers for online access to their record, the data should be checked for sensitive data before access is switched on. Such data should be redacted or the patient may be refused access.

Achieving the benefit of online access to the detailed coded record is dependent upon the practice maintaining good data quality. This includes being aware of the possible harmful impact of sensitive data at all times for all patients.

Box 1: Definitions

**Coded record** - For the purposes of Patient Online this is data in the patient clinical record which has been recorded using a clinical coding system (in the context of GP records this will mean Read V2 or CTV3 or SNOMED CT) or a drug coding system such as dm&d.

**Third Party Information** - Confidential information that was obtained from or is about someone other than the patient. It is not information that the patient has provided about someone else such as a family history of illness. For more detailed advice regarding third party information see “What should I do if the data includes information about other people?” of Information Commissioner’s Office Guidance.

**Introduction**

The [GMS contract](#) and [PMS agreement](#) for 2015-2016 require practices to promote and offer their registered patients online access to all coded data in their GP records, referred to as their detailed coded record by April 2016. This includes data recorded before access is switched on for the individual patient. An exception can be made where the record contains data that the patient will see that may be harmful to the patient in the opinion of their GP or contains confidential information about a third party. The record should always be checked and any sensitive data redacted before online access is switched on. If full redaction is not possible, a practice may refuse to give the patient access to the record. GP system suppliers are developing their systems to provide the required functionality. (For more information see the [RCGP Guidance on Protecting the safety of patients and the practice – Sensitive Data](#).)

Providing a patient with online access to their detailed care record is a healthcare intervention that may improve the patient’s understanding of their condition, and their ability to self care.

This guidance explains what patients may be able to see in their detailed coded record and the impact that may have on their healthcare and the practice. It does not cover access to the full medical record, which practices may offer if they wish.
The detailed coded record

Each supplier has interpreted the requirements to provide online access to the detailed coded record differently. The specification described by NHS England specification in the Patient Online support and resources guide is:

- Demographic data
- Investigation results including numerical values and normal ranges
- Problems/diagnoses
- Procedure codes (medical and surgical) and codes in consultations (symptoms and signs)
- Biological values (e.g. BP and PEFR)
- Immunisations
- Medication
- Allergies and adverse reactions
- Codes showing referrals made or letters received
- Other codes (ethnicity, QOF)

The record may be incomplete for some weeks after a patient changes practice unless the record was transferred by GP2GP. When the new practice summarises the record, the patient may notice that the record appears to lack much of the data it used to include, such as laboratory tests results from the previous practice. It is helpful to discuss Patient Online with new patients when they first register with the practice so that they know what to expect if they register for online access again.

Information that has only been recorded as free text will not be visible to the patient. Information that is important for the patient to see must be coded. Read codes can be ambiguous or difficult for the patient to interpret, e.g. arthralgia of the lower leg. They may be misleading if they are displayed online without free text appended to the code in the record. It is generally better not to use free text to qualify or change the meaning of Read codes. These and other aspects of data quality relevant to Patient Online, including summarising new patient’s records are discussed in the RCGP Guidance on Data Quality.

Data that has been hidden from display by the practice (redacted) will not be displayed online. The practice may also choose to redact data that may be harmful to the patient or may be confidential data provided by, or about a third person, to whom the practice has a duty of confidentiality. For further information please see RCGP Guidance on Protecting the safety of patients and the practice – Sensitive Data.

The GP system may not be able to display all the coded data to the patient. Consent and opt-out codes (unless they are marked as problem codes) and follow-up codes in the patient’s schedule may not be visible. This may have an impact on how the patient can use the data. For example, they may not be able to check when they are next due for a smear test or to attend the diabetic clinic. It is important to know the capabilities and limitations of your system.
Box 2: What does the patient see online?

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 configures 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.

Using the detailed coded record for healthcare

Patients may use access to the detailed coded record in various ways.

To find out what the GP record holds - Experience has shown that many patients look once at their record to see what is in it and check that it is accurate. They may find mistakes or something they disagree with or are upset about. It is helpful to make patients aware of this when they register for access to their detailed coded record and make sure that they know that the practice would like to hear from them if they come across anything like that and will welcome their feedback. It might be helpful to explain that the practice will not necessarily change anything that the patient disagrees with. Patients may ask for data to be deleted but it is up to the practice to decide if that is the right thing to do. There is more about the impact of data quality on Patient Online in the RCGP Guidance on Data Quality.

• To identify omissions and mistakes in the record - Patients may spot that a previous adverse reaction to medication and allergy, immunisations or other events in their medical record are missing from their record. They may understandably want the data to be added to their record but it is up to the practice to decide if that is appropriate. Similarly if a patient wants the practice to remove or change a data entry, the practice should make the decision about whether to agree to the request in the usual way.

• To check investigation results - Patients may want to check new results from ongoing investigations or monitor their progress in the management of long term conditions. It may help them to prepare for consultations and reduce the need for patients to telephone the practice for their results. Laboratory results can be hard to interpret (see box 1) but, with the help of the practice, patients can find the data very helpful. If your clinical system allows, you may wish to enable free text for laboratory results to facilitate this process.
Box 3: Interpretation of laboratory results

It may help to explain to patients that laboratory results can be difficult to interpret.

- Tests are carried out for different reasons and the meaning of the result may depend upon the circumstances of the test: diagnosis, monitoring, risk-stratification and screening. A result may be abnormal when used to make a diagnosis but acceptable for monitoring purposes, or vice versa.

- Reference intervals vary from laboratory to laboratory and may not allow for individual differences in age, gender and ethnicity. Generally 5% of the healthy population has a test that is outside the reference range.

- The predictive value of a test may vary depending upon the population. A test result may not distinguish between healthy people and those with disease. A false positive or false negative may be upsetting or inappropriately reassuring for the patient.

- Monitoring tests may vary with time quite normally. Patients may find it difficult to decide whether a change in level is normal, e.g. a rise in total cholesterol from 5.7mmol/L to 6.1mmol/L.

- Risk stratification is often based on several factors so for example two people with the same high total cholesterol may have very different cardiovascular risks.

- Screening tests are recommended on a set of criteria, including the predictive value of the test and the benefit of early recognition. Some tumour markers are useful in monitoring disease but not in making a diagnosis.

- Free text results may not be displayed correctly in Patient Online if free text is not enabled. This is most common with microbiology reports.

Reference: Explaining laboratory test results to patients: what the clinician needs to know. (BMJ, 2015;351:h5552)

- To review the recorded problems and diagnoses - Patients may need to be able to report their medical history to complete a form for insurance, loans or legal matters. They should understand that the problem and diagnosis lists in the online record are not designed for this purpose; they may be incomplete due to redaction as discussed above, or they may contain things that may be misunderstood or misleading in such reports. If in doubt they should check with the practice before relying on what they see online. Nevertheless patients do find it useful to have access to their full problem summary, especially if it is well maintained by the practice.

- To monitor the progress of long term conditions - Codes recorded in the consultation can be very useful for the practice to communicate with the patient or as the basis of a shared care record in long term conditions or palliative care. Box 4 contains an example of codes that contribute to an online care plan for diabetes mellitus. Signs, symptoms, biological values such as blood pressure, PEFT, FEV1 or BMI help patients monitor their progress. So do laboratory results.
Codes about decisions to refer or stages in patient care such as a review interval or minor procedure carried out can act as a reminder for the patient. Patients will need help to understand the meaning of the codes. Information prescriptions like those provided by Diabetes UK can be helpful.

### Box 4: Codes for a diabetes care plan

<table>
<thead>
<tr>
<th>Term</th>
<th>Read V2</th>
<th>CTV3</th>
<th>SNOMED CT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes self-management plan agreed</td>
<td>661M4</td>
<td>XaYb</td>
<td>811981000000102</td>
</tr>
<tr>
<td>Pt advised re diabetic diet</td>
<td>8CA41</td>
<td>8CA41</td>
<td>no code</td>
</tr>
<tr>
<td>Dietary advice for diabetes mellitus</td>
<td>no code</td>
<td>Xa2h7</td>
<td>no code</td>
</tr>
<tr>
<td>Dietary advice for type II diabetes</td>
<td>no code</td>
<td>Xa2hA</td>
<td>no code</td>
</tr>
<tr>
<td>Diabetes mellitus diet education</td>
<td>no code</td>
<td>no code</td>
<td>284350006</td>
</tr>
<tr>
<td>Diabetic lipid lowering diet</td>
<td>13AB.</td>
<td>XaFvj</td>
<td>315207000</td>
</tr>
<tr>
<td>Diabetic weight reducing diet</td>
<td>13AC.</td>
<td>XaFvk</td>
<td>315208005</td>
</tr>
<tr>
<td>Diabetic dietary review declined</td>
<td>8IAs.</td>
<td>XaX3r</td>
<td>754141000000100</td>
</tr>
<tr>
<td>Patient advised re exercise</td>
<td>8CA5.</td>
<td>8CA5.</td>
<td>no code</td>
</tr>
<tr>
<td>Lifestyle advice regarding exercise</td>
<td>67H2.</td>
<td>XaJlt</td>
<td>no code</td>
</tr>
<tr>
<td>Exercise education</td>
<td>no code</td>
<td>no code</td>
<td>304507003</td>
</tr>
<tr>
<td>Goal achievement finding</td>
<td>67V..</td>
<td>XaIOX</td>
<td>no code</td>
</tr>
<tr>
<td>Goal achieved</td>
<td>67L0.</td>
<td>XaIOZ</td>
<td>390802008</td>
</tr>
<tr>
<td>Goal not achieved</td>
<td>67L1.</td>
<td>XaIOY</td>
<td>390801001</td>
</tr>
<tr>
<td>Identifying personal goals</td>
<td>67L2.</td>
<td>Xabhz</td>
<td>928061000000100</td>
</tr>
<tr>
<td>Assessment of Year of Care goal importance</td>
<td>38L..</td>
<td>XaZTk</td>
<td>842271000000109</td>
</tr>
<tr>
<td>Identifying barriers to goal achievement</td>
<td>67R..</td>
<td>XaYal</td>
<td>811791000000103</td>
</tr>
<tr>
<td>Review of patient goals</td>
<td>8CMX.</td>
<td>XaXfH</td>
<td>775501000000108</td>
</tr>
<tr>
<td>HbA1c (haemoglobin A1c) target level - IFCC</td>
<td>66Ae0</td>
<td>XaWP9</td>
<td>446074002</td>
</tr>
<tr>
<td>3 month target weight</td>
<td>66CF0</td>
<td>XabP3</td>
<td>918691000000107</td>
</tr>
<tr>
<td>6 month target weight</td>
<td>66CF1</td>
<td>XabP4</td>
<td>918711000000109</td>
</tr>
<tr>
<td>12 month target weight</td>
<td>66CF2</td>
<td>XabP5</td>
<td>918731000000101</td>
</tr>
<tr>
<td>Target weight to achieve five percent weight loss</td>
<td>66CF3</td>
<td>XabaK</td>
<td>923881000000105</td>
</tr>
<tr>
<td>Target weight to achieve ten percent weight loss</td>
<td>66CF4</td>
<td>XabL</td>
<td>923901000000108</td>
</tr>
<tr>
<td>Target body mass index</td>
<td>22KA.</td>
<td>XaZMj</td>
<td>838441000000103</td>
</tr>
<tr>
<td>Target cholesterol level</td>
<td>662X.</td>
<td>XaiQb</td>
<td>390896004</td>
</tr>
<tr>
<td>Target serum total cholesterol level</td>
<td>no code</td>
<td>XaXbu</td>
<td>no code</td>
</tr>
<tr>
<td>Target physical activity</td>
<td>13CI.</td>
<td>XalUT</td>
<td>391105003</td>
</tr>
</tbody>
</table>
Box 5: Scenario

Jane Smith is a 32 year old diabetic student who has just moved to a new city with her work. At her home practice she has been accessing her detailed coded record which she has used to view her results.

Jane registers at a new practice at university and requests access to her coded record.

Her record is received on paper as her home practice does not use GP2GP electronic record transfer. When Jane logs in to view her record she cannot see her previous results to monitor her progress. She can see the values for her latest results taken at the new practice, so depends on her own knowledge and understanding to interpret them. She asks for specific important old data to be coded on her record such as the date of her last digital retinopathy screening and the result and key elements of her shared target are coded at her next consultation.

- To check their immunisation status - These data can be very helpful for people who want to check their immunisations are up to date or what they have been immunised against, e.g. when they are planning foreign travelling or new employment or for parents with proxy access to the records of their children.

Information governance

Free Text - may be appended to coded data, which by default will be displayed as part of the detailed coded record. It may have been added to explain or qualify a coded entry, for example some investigations may be reported as a code for the test with the result in free text, so to provide a meaningful entry the associated free text is required. This may contain potentially harmful or third party information in another context.

Where the GP clinical system gives the option to enable or disable free text the benefits and risks need careful consideration. When enabling free text, there is a definite benefit in terms of the clarity of the record, but there is an increased workload implication in ensuring the appropriate redaction of confidential third party or potentially harmful information (see the RCGP Guidance on Protecting the safety of patients and the practice – Sensitive Data).

Where technically possible it may be desirable to restrict the enabling of free text either by date or by content type.

It is important that the patient understands the extent of free text display in their online records and the implications for the meaning of the record.

Sensitive information - Whether the information in a record is sensitive or not is often a matter of context and opinion. In the case of online records access the opinion that matters is that of the patient. Some patients, particularly vulnerable patients, may be aware that they will not be the only ones viewing their online records. It is therefore essential that patients know what is in the record and how they can request that the practice hide (redact) sensitive information from online viewing.

For more information see related guidance on Proxy Access, and Coercion.
Data Quality

Data quality and ongoing maintenance of the coded record is very important to provide the patient with the most helpful clinical record online. This includes appropriate redaction of sensitive item.

Once the practice has enabled records access all members of the team must be aware that any patient may ask for access and their records will be available to them online. Patients may already ask for a paper copy of their record as a Subject Access Request under the Data Protection Act, but these requests are rare and the task of checking for an redacting sensitive data is not onerous. Patient Online may increase the workload of checking records significantly enough for time pressures to allow sensitive data to be missed. This will affect how they create and maintain records in the future. For more detail on how online access to records impacts on records quality see the RCGP Guidance on Data Quality.

Transferring patient records

As the GP2GP electronic transfer of electronic records becomes the norm when patients change practice, practices will need to consider the implications of online access in this process.

Outgoing records - Practices need to be aware that free text and confidentiality settings may not transfer with the record, therefore information which has not previously been visible to a patient online may become visible when they move practice. When registering a new patient for online access they need to be aware that the record they see may be different as a result.

Incoming records - When receiving a new record by electronic record transfer the receiving practice needs to check the online access setting for the records and apply the guidance as they would for any newly online access registration. A new decision will normally have to be made about whether any data needs to be redacted. Maintenance may need to be carried out on the data quality of the record. Practices also need to be aware that degraded codes may disappear from the patient's online view.

Summary

From April 2016 there is an obligation on all practices to be able to make online access to the coded record available to patients requesting it where appropriate. Practices must have a full understanding of the issues relating to this access, both in terms of the benefits and how these can be promoted, and the risks. They also need to be aware of what their principal system supplier offers for extending access beyond the required coded record and how this may be used safely to enhance the benefits of online record access for patients.
Further information and resources

- Proxy access guidance for general practice
- Coercion guidance for general practice
- Records access Patient information leaflet
- Data Quality guidance for general practice
- Protecting the safety of patience and the practice – Sensitive Data guidance for general practice
- Explaining laboratory test results to patients: what the clinician needs to know
- GMS contract 2015/16
- PMS agreement 2015/16
- NHS England Patient Online support and resources guide
- Diabetes UK