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NHS England

Patient Online:
OFFERING PATIENT ACCESS TO DETAILED ONLINE RECORDS

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Equality and Health Inequalities Statement
Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

This guide is designed to provide GP practices with the support and guidance required to offer patients online access to their detailed coded record. It is intended as a generic guide as there may be differences in the actual process according to the clinical system that the practice has in place.

The guide will also support clinical commissioning groups (CCGs) and commissioning support units (CSUs) working with practices to implement high-quality online services.

This guide contains content that has been drawn from a range of available sources including practices that are already providing their patients with online access to their full detailed records. Links to other relevant sources of information are provided in this guide and others will be added over time. It may useful to check the link to this set of resources from time to time to ensure that you have the most up-to-date information and guidance.

The following additional guides are available as part of the Patient Online Support and Resources Guide 2015/16:

1. Patient Online: making the most of online appointments and repeat prescriptions
2. Patient Online: registering patients for GP online services

Online services for patients not only improve the quality of care through enhancing patients' experience of services, but also enables practices to realise benefits such as reducing administrative workload. There are a number of examples where practices have already provided patients with access to their detailed coded online record and are now seeing the benefits for both patients and practice staff. View the video about Street Lane Practice in Leeds and read about their story here.

NHS England Patient Online team is available for support and guidance. In addition, CCGs and CSUs also offer local support and guidance for practices.

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What does the GMS contract and PMS agreement for 2015-16 say to practices?

The GMS regulations 2015-16 state that practices must promote and offer to patients the facility to view their detailed coded online record by March 2016[1]:

- A contractor must promote and offer to its registered patients, in circumstances where the GP records of its registered patients are held on the contractor's computerised clinical systems, the facility of any such patient to access online all information from the patient's GP record which is held in coded form unless:
    - In the reasonable opinion of the contractor, access to such information would not be in the patient's best interests because it is likely to cause serious harm to:
    - The patient's physical or mental health, or
    - The physical or mental health of any other person.
- The information includes a reference to any third party who has not consented to its disclosure, or:
- The information in the GP medical record contains a free text entry and it is not possible under the contractor's computerised clinical systems to separate that free text entry from other information in the record which is held in coded data form.

Getting ready – what do practices need to do?

GPs who are the 'business owners' are Data Controllers under the terms of the Data Protection Act 1998 and therefore have overall responsibility for ensuring that all data processing is undertaken in accordance with the Act. The policies and procedures adopted by the practice for Patient Online services should be approved by the Data Controller prior to implementation.

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[1] http://www.nhsemployers.org/~/media/Employers/Documents/Primary%20care%20contracts/GMS/Other%20GMS%20related%20Documents%20and%20Directions/2015-16/201516%20General%20Medical%20Services%20Regulations.pdf

Policies and processes

- Ensure that policies and processes are in place and that staff are aware of these and understand what they need to do to make the detailed coded online records available to patients who request it.
- Agree policy review dates to ensure that the policies/protocols remain aligned with any revisions to regulations and/or other changes in local practice.
- Ensure all staff are made aware of any version upgrades or changes in policy or processes and how this might affect what they are doing.
- Agree how records should be checked prior to granting access to patients.
- Agree who is able to grant access to detailed coded information or the full record. The nominated staff/roles should be included in the practice policy document, e.g. GP to authorise full access.
- Some groups of patients may benefit from online access to their detailed records, particularly those patients with long term conditions. Agree within the practice how and when these patients should be asked if they would like to have access and include this in practice procedures or process statements.

Your clinical system

- Check that your clinical system is enabled for detailed coded online records and that any changes to working practices are clearly documented and understood by practice staff.
- Provide all staff with the time to familiarise themselves with the user guides that have been provided by system suppliers.
- Most system suppliers offer a range of promotional materials so ask to be provided with relevant resources.

Promoting the service

Promotion is a key success factor in encouraging patients to register for online services, particularly access to records. The following resources and ideas may be useful when deciding how to promote online access to records within practices:

- Communications toolkit which includes example newsletter articles, and tweets for local use. Information for patients will also be included in the communications toolkit. You can also view a Word version here.

The following are examples from practices already providing patients with online access to their detailed records:

- Appoint a Patient Online champion or super-user within the Practice (e.g. a patient participation group member, member of staff or volunteer) to help patients register for online services when they visit the practice.
- Discuss with your patient participation group (PPG) and encourage members to use online services themselves. This is particularly useful for testing current or new processes prior to offering the services to the wider patient population.
- Encourage all staff to promote online services during face-to-face interactions as well as on the phone.
- Ask local organisations such as pharmacies, post offices, voluntary agencies and libraries if they will help you promote online services by displaying posters in their premises.
- Include a message on the telephone management system – either as the first thing the caller hears when they are connected or/and when they are on hold.
- Ask PPG members for feedback when developing/expanding online services and support materials as they can be influential in encouraging other patients to use online services.

- Include information about online services; what is available and how to register on the practice website.
- Regular updates/information in practice newsletters.
- Include a message on prescriptions.
- Include a poster/message on the reception TV screen.
- Use Twitter/Facebook to promote online access.
- The practice nursing team is ideally placed to promote online services routinely for all patients with long term conditions, to support improvement of self-care and management.

Providing access to the detailed coded online records

Access to the detailed coded information in the record is not time-stamped. Once access is given to the patient, they will be able to view ALL clinical coded information in their record. The only exception to this is where providing this information may cause harm to the patient or identify a third party who has not given permission to disclosure.

Clinicians need to have a clear understanding of what information is available to patients when granting access to the detailed coded record. The following tables are examples of both coded and non-coded information.

Detailed coded data – EXAMPLE

This is an example of categories of information that patients may see. This may be presented differently by each supplier.

- Demographics
- Allergies/adverse reactions
- Medication (dose, quantity and last issued date)
- Immunisations
- Results (numerical values and normal range)
- Values (BP, PEFR)
- Problems/diagnoses
- Procedure codes (medical or surgical) and codes in consultation (signs, symptoms)
- Codes showing referral made or letters received (no attachments)
- Other codes (ethnicity, QOF)

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Not required from coded data – EXAMPLE

The following categories are examples of items that are not required to be displayed. However, you may choose to make them available.

Free text

Letters and attachments

Administrative items

- Diary entries/recalls
- Special notes/warnings
- Tasks/emails/ internal messages

Experience has shown that few patients query the clinical content of their record. However, to ensure that any queries are addressed, it would be good practice to identify who should respond to these types of queries in the practice policy.

Deciding on record access

When a patient requests access to their record someone at the practice needs to decide if the patient can have access and what level of access they can have. This will often be a clinician but it could also be a suitably trained non-clinician with support from a clinician when needed. The practice policy should detail who authorises levels of access.

Patients can be given any of the following levels of access to their notes

Levels of access to records

Some patients	Full record access	All coded information Free text Documents (3rd party and sensitive content excluded)
Most patients	Detailed coded access	All coded information (3rd party and sensitive content excluded)
Few patients	Summary information or no record access	

The level of access will depend on decisions made at the practice (such as whether to offer free text or documents), the individual patient and the contents of their record. The vast majority of patients can be given full record access or detailed coded record access. Both meet the requirements of the GMS contract. A few patients will require more restricted access and on rare occasions no access. This should only be done if greater access would cause harm to the patient. Practices need to be prepared to explain their decision to the patient and demonstrate that they have done so through a standard process that is non-discriminative.

Discussing limited or no access with the patient

Practices have expressed concern over the potential conflict with patients if record access is denied. Hopefully this guidance will provide assurance that there are very few patients that this will apply to, particularly with the options of redacting third party and sensitive information or giving restricted access. The **patient information leaflet** and **access to sign up form** which are available to download for local use already encourage the patient to consider the implications of their request for record access.

Involving the patient early in the process is also a way of avoiding conflict. In cases where a patient is refused access (or given significantly restricted access) there should ideally be a face-to-face discussion between the clinician and the patient. While this uses valuable clinical time it is far less time consuming than dealing with appeals and complaints further down the line.

The only reason for denying access is if it's in the best interest of the patient. It may be that the risks concerning the clinician are not a concern for the patient or, the patient can mitigate against them, for example the abused wife who is confident that accessing her record only from work provides protection from safeguarding or the patient may decide the benefits out way the risks.

Free text

Free text is not a contractual requirement but can add value and meaning for patients and so bring more benefit for practices. It may not be suitable for all patients or the practice may decide initially to only give free text access prospectively.

Checking free text requires more time and is more difficult to automate. It is more likely to contain sensitive or third party information that needs to be redacted.

Documents

Documents are essentially the same as free text and so the above considerations apply. However, letters from external agencies are legally third party data (it is the sender of the letter who is the data controller) and so the permission of the sender needs to be gained before sharing.

Many letters are now automatically shared with the patient and so granting patients online access to these would not require permission. If the providers sending letters have been informed that by default their correspondence will be shared unless they specifically indicate otherwise then this would also remove the need to seek permission (though potentially only prospectively as it is unlikely that permission has been granted for letters preceding online access).

This guidance states the legal position as it currently stands but it is recognised that current practice may already be different to this. There is already discussion and debate around the record being the property of the patient. Guidance in this area may change over time.

Third party information

Before giving access, you should check the patient’s record for third party information. This is information about individuals other than the patient. The law requires that this must be excluded where disclosure would breach confidentiality.

Details provided by someone such as a partner or carer about themselves or somebody else are an example of third party information that should be excluded. Information about third parties provided by the patient usually need not be excluded, as access to this by the patient would not breach confidentiality. If you have any doubt about whether disclosure to the patient would breach confidentiality, it should be excluded.

Entries made by care professionals, including additions to the record such as letters from other organisations are not third party information. These are created with the understanding that the patient has a right to see them. As data controller, it is up to your organisations to ensure that third party data is appropriately reviewed and removed. You must also consider whether any release of data would cause harm or distress to the patient or a third party. This harm/distress judgement must be recorded.

Similarly, information about the patient provided by someone who is not a care professional need not be excluded, but the identity of the person should be excluded.

Proxy access

Guidance is available separately for [proxy access]() but greater attention needs to be given to proxy access requests for detailed coded record access, and this is especially true if free text is enabled. In many cases it will be in the patient's best interest but it is not a contractual requirement and so practices can decline (with an explanation) if there are concerns.

Safeguarding

Safeguarding is also covered in [separate guidance]() but in terms of record access the additional information involved means there is greater risk of harm to the patient if they are coerced into sharing their record and it contains information that is sensitive.

If a patient is at risk of safeguarding then consideration needs to be given to not only whether the content in the record might harm the patient directly but also to the consequences of someone else gaining access to that information. The most obvious examples would be abusive relationships and issues around safeguarding.

Sensitive information

This refers to information contained in the patient's record that could cause them harm (usually emotional but may be physical in the case of safeguarding by an abusive partner). Below are potential examples of areas to consider

- Child and adult safeguarding
- Domestic violence
- Sexually transmitted infections
- Terminations / stillbirth / death of children
- Fertility treatment
- Alcohol abuse / illegal drug use
- Criminal activity
- Gender issues and sexuality
- Serious mental health problems

This list is by no means comprehensive. The presence of sensitive information does not mean that the patient cannot have record access or even that the information must be excluded from the patient view; the decision may be different for different patients. For example, an entry of 'termination of pregnancy' may be upsetting to one person but not another. An entry of 'facial bruising' is much more sensitive if there are also entries about safeguarding or domestic violence. An entry of 'patient is adopted' could be very harmful if that patient does not know they are adopted but may be of no significance if they do.

These decisions require a judgement to be made. The Information Commissioner's advice is that practices need to be able to demonstrate that the processes in place to review patient notes are applied universally and fairly. All reasonable effort has to be made to minimise harm and prevent disclosure of third party information.

Things to consider:

- The patient has a right to submit a Subject Access Request under the Data Protection Act 1998. This differs from accessing online services in that to obtain a copy of their medical records; the patient must put this request in writing to the practice. The practice can charge a fee for providing the information in a printed form. Patients accessing their records online are able to copy and paste or print the information from the screen and there is no fee for this.

Further information for patients about the different methods of accessing their records is available on the [NHS Choices website]().

- Practices will be able to review and remove access at any point in the future if they think that it is in the best interests of the patient.
- Once the practice has undertaken the appropriate checks and the patient has been informed that access has been enabled, it may be a helpful reminder to provide the patient information about [their responsibilities for accessing their detailed coded record]().
- Patients may also choose to have access to some or all of the online services removed for them at any time.

Improving access

It can be helpful to monitor your online services to see how they may be adjusted to further benefit your practice and patients. For example:

- Think about how you can gather feedback from staff and patients to test how well your processes are working and how they may be improved.
- Agree a procedure with your PPG to collect suggestions for improvements and how they can be implemented and publicised.
- Ask patients if you can contact them for feedback a few months after they register for online services or build a standard question into your GP Patient Surveys. Their feedback can provide ideas for improvement or be the basis of case studies to help you promote to other patients.
- Liaise with other practices during practice manager meetings and system user group meetings to share improvement ideas.
- Suggest improvements to system suppliers based on experience of providing online access to patients.

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- When monitoring the success of online services, the following measurements might be useful:
    - Total percentage of patients with access
    - Percentage of patients with access by demographic
    - Percentage of access/viewing against patients registered for records access
    - Results from GP patient survey
    - Feedback from patients and staff
    - Results from the Friends and Family Test
- Discuss your experiences and findings with other practices.