Patient Online

Information Governance

v2.0

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Introduction

The purpose of this guidance is to describe practice’s legal and formal responsibilities in relation to the processing of confidential patient information in offering and providing online GP services. It is intended for the practice Patient Online lead and Caldicott Guardian but is relevant to the roles and responsibilities of everyone working with Patient Online.

It covers the practice’s processes for:

1. Management of new applications for Patient Online services by patients and people acting on their behalf
2. Information governance of the records of patients who already have Patient Online access
3. Supporting patients’ appropriate use of their Patient online access.

Information governance is the term used to describe how organisations manage the way information is handled within health and social care. It covers the behaviour and standards needed to ensure that confidential information is handled legally, securely, efficiently, effectively and in a way which maintains public trust. It is based on the balance established in law between privacy and sharing of confidential data which is fundamental to health and social care.

Patient Online does not change the right that patients already have to request access to their medical records under data protection legislation. It does not meet the requirement to provide access to the complete record but it does bring a new dimension to practice responsibilities for information governance. Far more patients ask for online access to their record than used to ask for their paper record, and they look at their records more often.

Practice policies and any associated guidelines on information governance should be updated to cover Patient Online. All staff members need to understand what to do, particularly in circumstances that may be unfamiliar to them.

If doubts arise about how to manage a specific event, you can seek specialist advice on information governance issues from Local Medical Committees, medical defence organisations, or the clinical commissioning group (CCG) Caldicott Guardian or the General Medical Council. NHS England’s GP online services team offer support for practices (email: england.patient-online@nhs.net) and advice can be sought from the Information Governance Alliance, a team drawn from the Department of Health and Social Care, NHS England and NHS Digital (email: IGA@nhs.net).

Signing up patients for Patient Online

The principles of information governance are very important in signing up patients for Patient Online:

1. Always actively seek evidence of coercion o the patient to allow someone else to have access to their GP online services unwillingly and act on any suspicion that this may happen
2. Take extra care when signing up applicants for record access because of the risk of exposure of particularly sensitive confidential patient information.
3. Verify the applicant’s identity to ensure they relate to the record on your practice computer system that they are asking to access
4. Clinically assure that the record is ready for the patient to read before signing the patient up for record access.
5. Provide information to ensure that the patient knows how to use Patient Online, keep their Patient Online access secure, understand the health information it contains and knows that the practice are ready to discuss any questions the patient may have about their record
6. **Deliver login credentials** to the patient securely, by the method of their choice, by hand, post or email, ensuring that the patient understands the risks of each method of delivery.

7. Assess and provide **proxy access** by someone acting on behalf of the patient appropriately. This may be a carer, partner or parent, appropriately.

8. Under GDPR, **children** under the age of 13 must not be given control of an internet service such as Patient Online.

There is more information about signing up new patients for Patient Online in the section of the Toolkit on Registering New Patients for Patient Online.

**Coercion**

This is probably the greatest risk to patients who have Patient Online and is particularly important to remember when someone applies for record access. It is the act of governing the actions of another by force or by threat, in order to overwhelm and compel that individual to act against their will. In this context, coercion might result in patients being forced to share access to their record, including login details, medical history, repeat prescriptions, and GP appointment. It gives someone abusing the patient the ability to control their access to healthcare.

Coercion to share or misuse access to Patient Online is most likely happen if the patient is a child, an adult in an abusive relationship, or an elderly or otherwise vulnerable adult.

You may already have processes in place to manage safeguarding risks of suspected coercion relating to paper-based and face-to-face services but Patient Online creates new and additional opportunities for coercive behaviour that must be addressed specifically. Everyone in the practice who signs up patients for Patient Online must be aware of the possibility of coercion and actively seek indications of it.

Always discuss the issue of coercion with patients who ask to sign up for Patient Online. and ensure that they understand and accept the risks. Every new applicant should be asked a question to raise the issue of coercion such as “Is it possible that you may come under pressure to give someone access to your personal information in Patient Online against your will”. The question should be included in a registration form for online services for patients.

Any suspicion or evident risk of coercion must referred to the practice Patient Online lead or a senior clinician who knows the patient to consider withholding Patient Online at least until the situation can be thoroughly investigated and assessed. It may be possible to sign the patient up to Patient Online access may be limited. Any data indicating abuse must be redacted.

There is more information about Coercion and a template for a new application form in the Toolkit. RCGP, NICE, Safelives and IRIS (Identification & Referral to Improve Safety) have published guidance for practices to help effective response to patients experiencing domestic abuse (see Resources below). There is more information on the management of harmful data in the guidance on Safe Patient Online Record Access in the RCGP Toolkit.

**Identity verification**

Providing access to Patient Online demands a consistent and robust approach to ensure that the person applying for access to a patient’s GP online services is the person that the record relates to.

Patients may book an initial appointment online as soon as they have completed a simple online registration process but a stronger identity verification process is required before full
access to appointments, repeat prescriptions or clinical records is switched on.

In future patients may use the NHS App to verify their identity but the practice can use any one of three methods that can give them certainty that the applicant is who they claim to be.

1. Most patients can prove their identities by presenting **two forms of documentary evidence**: one must include a photo that clearly matches the patient and the other must confirm that the applicants address is the one that you have on your records. Acceptable documents include passports or photo driving licences with photographs and documents bearing the address that are likely to have been posted to the patient such as a bank statement. Bills will not meet this criteria. A full list of acceptable documents is published by the Cabinet Office (see further reading).

2. There will always be some patients (e.g. temporary residents, travellers or young people living with their parents) who do not have acceptable identity evidence. In these cases, an authorised member of staff, who knows the patient well enough to verify that they are who they say they are, and that no deception is taking place, may be able to **vouch for their identity**. Practices must judge each patient on a case-by-case basis while ensuring that the agreed policy takes into account the duration of registration and frequency of patient contact.

3. If neither of these two methods of verification are possible, consider **using information in the patient’s health record** to verify the identity of the applicant. A trained member of staff may be able to satisfy themselves of the applicant’s identity by obtaining responses to questions from information held in the medical records. This should take place discreetly and ideally in a planned appointment. It is extremely important that the questions posed do not incidentally disclose confidential information to the applicant before their identity is verified.

There is more information about this in the Identity Verification guidance in the Toolkit.

**Clinical assurance of the record**

This is an essential process to complete before record access is switched on to assure the clinical record is fit to be shared with the patient. The purpose is to ensure that the patient is not exposed to any sensitive data that may cause them harm or reveal confidential information relating to a third person, which they have no right to see.

Clinical assurance of large records 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.

Redaction of specific data items hides them from online access by the patient or other health and social care organisations. The data is not deleted from the record or hidden from practice team members. It remains available for use in patient care in the practice.

Redaction may be reversed after discussion with the patient. For example, an abnormal test result that might upset a patient if unexplained my be redacted until there is an opportunity to explain what it means to the patient. Redaction may occasionally need to be permanent, particularly for confidential third party data.
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.

Informed patients

Patient need to know how to use Patient Online safely, to protect their access and keep their data secure. If patients want to be able to use Patient Online but lack the computer skills that they will need, they may be able to use a local centre to learn to use computers securely. There is a network of learning centres throughout the UK co-ordinated by the Good Things Foundation (see further reading below).

Patients who have Patient Online have responsibility for the security of confidential health information that they can access and they need to know how to protect it. They should also be aware that the information they see may be harmful or upsetting, they see information that they disagree with, that is incomplete, or inaccurate. They may identify things that are missing that they would like to have in the record such as allergies or past vaccinations. They may see confidential information relating to a third person that they should not have access to. The practice should make sure that patients are fully informed about all these possibilities when they apply for Patient Online.

There is more information about the information that patients need to use Patient Online in the guidance on Patient Information for Patient Online in the Toolkit.

Tried and trusted techniques such as “chunk and check” and “teach back” help patients retain information about their health and GP services. Verbal advice about Patient Online should be backed up by accessible written information on paper or on the practice website, which patients with a visual disability often prefer. Patient leaflets, posters, websites and any other means of communication available to the practice can be used to communicate with patients about Patient Online.

You can view and download PDF versions of free patient leaflets and promotional materials about Patient Online produced by NHS England at https://www.england.nhs.uk/gp-online-services/support/supporting-material/patient-information-guides/ and order paper copies for patients by following the Orderline link on the NHS England webpage.

There are also more guidance on Patient Information in the Toolkit and templates for patient leaflets on understanding abnormal laboratory results and other topics.

Patients can use their detailed coded record as a list of terms to learn about to 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 their record itself.

There is more information about how to support health literacy in the RCGP Person-Centred Care Toolkit, (http://www.rcgp.org.uk/clinical-and-research/resources/toolkits/person-centred-care-toolkit.aspx).

Useful websites that patients can rely on for information about a wide range of health matters include

- https://www.nhs.uk
- https://patient.info
- https://labtestsonline.org.uk
Proxy access

Some patients find it helpful for a second person to have access to their Patient Online account. This is called proxy access. It may be an informal arrangement by which the patient shares their log in credentials with their proxy and the practice may know nothing about it or, if the GP system has the capability, a more formal arrangement where the practice give the proxy their own personal log in credentials and sets the proxies level of access, which may be different to the patient’s access.

This normally requires the patient’s consent but, in some circumstances,, where the patient is not able to consent, the practice may make the decision to allow proxy access if it is clearly in the best interests of the patient. The decision is made more easily if the patient made an advanced decision to allow a named individual to have proxy access when their health deteriorated so that they are no longer able to manage their own healthcare, or if the proxy has a lasting or enduring power of attorney or is a Court Appointed Deputy. It is also possible to allow proxy access for a child up to their 11th birthday to someone who has parental responsibility for the child.

Where proxy access is being considered for direct care by health professionals with a legitimate relationship with the patient, access should only be named individuals and a data sharing agreement should be completed by the practice and the health professional or their organisation. **Children** - It is also possible to allow proxy access for a child up to their 11th birthday to someone who has parental responsibility for the child. As young people mature in their teens, there may be something that they do not want their parents to know about, parental access to their GP online services may inhibit their use of health services. To avoid this, you should switch off parental proxy access to a child’s Patient Online services at their 11th birthday. It is helpful to write to patient’s parents six months earlier to tell them that it will happen. This gives them time to ask the practice if they feel that in their child would benefit from continued proxy access.

There is more information about this in the Proxy Access, the Children and Young People and the Patient Online. There is information about sharing Patient Online access for direct care with organisations such as nursing homes in the Dementia guidance in the Toolkit. There is also a template consent form in the Toolkit that you can use to record the patient’s consent to their proxy receiving access to their Patient Online.

Patients who already have Patient Online access

Practices have a continuing responsibility for patients who have active Patient Online access. **Safeguarding** - It is always sensible to be aware of the risk to vulnerable patients where access to their GP services or records through Patient Online may be used by someone as part of a pattern of abuse. If a safeguarding risk arises or is suspected, or where there is suspicion that a patient may be subject to coercion to allow someone to have access to their Patient Online unwillingly, the practice may have to withdraw or restrict the patient’s access. It may be possible to allow access to appointments and prescriptions, withdrawing record access, at least temporarily until the situation can be investigated.

**Record data quality** - Patients appreciate high quality, complete, accurate and unambiguous record data that clearly represents their health history. Staff should take care to avoid the use of abbreviations and euphemisms that may be misunderstood by patients and avoid recording third-party data. It is not always easy to know if a patient has online record access and it is impossible to know who may have access in the future. Consider ensuring that all clinical records are fit for
sharing with patients. This includes the redaction of any sensitive data that may harm the patient or reveal confidential information about a third person.

Some data may be particularly harmful for patients who are subject to abuse. Always consider redacting records that refer to any suspicion or actual abuse. Data that is confidential information about a third party that the patient has no right to know should always be redacted. If it is not possible to redact some sensitive data it may be best to refuse or restrict record access for that patient. Abnormal test results can cause undue worry to patients if they see them online before they have had an opportunity to discuss them with a clinician. It is usually best to redact them until they can be discussed.

There is more information on the management of data quality in the Data Quality guidance and sensitive data in the guidance on Data Quality and Safe Patient Online Record Access in the RCGP Toolkit.

**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) recorded in the patient’s record; or consultation data, test results or scanned documents 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 the possibility that the patient will see the information if they have access to their records. There are four steps that you can take:

- 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.

There is more information about how to report a breach of personal data to the Information Commissioner at https://ico.org.uk/for-organisations/resources-and-support/pdb/

**Legal, insurance and employment reports**

Patients may consider using the clinical record information that they can see in Patient Online to complete applications or reports for legal matters, insurance, financial arrangements or employment. They should be advised against it and in particular they should not use a print out of their available Patient Online record in place completing a personal health report form.
There are several reasons for this advice. Patient Online does not display all the information in the GP record. A printed report may be assumed incorrectly to be equivalent to a subject access request report.

Significant information may have been redacted. The information that is available to the patient may not be presented in a way that makes it possible for the patient to summarise its contents. All these possibilities mean the the report may be incomplete, which may put the patient at risk.

The language of the information displayed by Patient Online is often technical and may be mis-interpretated by the patient. A patient may include something in the record that they do not fully understand and unintentionally give the wrong impression of their health to the recipient of their report.

Finally the report may be mistakenly attributed to the practice and deemed to be a medical report by whoever the patient shares it with.

Disclaimer

This guidance is a public resource providing general information and not advice relating to specific issues. Users of this guidance should consider taking advice tailored to their particular circumstances. This guidance is intended, but not promised or guaranteed, to be correct and up-to-date at the time of its publication. The Royal College of General Practitioners does not warrant, nor does it accept any responsibility or liability for, the accuracy or completeness of the content or for any loss which may arise from reliance on information and material contained in this guidance.
Further reading

Information Governance Policy

Royal College of General Practitioners, Patient Online: The Road Map 2013, is available in the Patient Online Toolkit


Information Commissioner’s Office 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 23 October 2018)

Coercion

RCGP has several resources on its website on domestic violence and safeguarding adults and children that are relevant to the topic of coercion - accessed on 23 October 2018 at http://www.rcgp.org.uk/clinical-and-research/resources/a-to-z-clinical-resources/domestic-violence.aspx

NICE has succinct advice on recognising and responding to evidence of domestic violence or abuse (https://pathways.nice.org.uk/pathways/domestic-violence-and-abuse) and in their guidance on Domestic violence and abuse: multi-agency working - PH50 (https://www.nice.org.uk/guidance/ph50).
Safelives provides many useful resources on coercion and domestic abuse, including resources for GPs and guidance on identifying domestic abuse (http://www.safelives.org.uk/policy-evidence/policy-and-research-library)

IRIS (Identification and Referral to Improve Safety) is a charity offers a general practice-based domestic violence and abuse (DVA) training support and referral programme that has been evaluated in a randomised controlled trial(http://www.irisdomesticviolence.org.uk/iris/).

Identity Verification


Information for Patients

Suppliers of Patient Online systems offer information for patients to help them use their systems:

- Evergreen Life/i-Patient (accessed on 10 October 2018 at https://e-life.co.uk/Help)
- SystmOnline (accessed on 10 October 2018 at https://systmonline.tpp-uk.com/2/help/help.html)
- Engage Consult (accessed on 10 October 2018 at https://www.wigglyamps.com/product/engage-consult/)
- Patient Services (accessed on 10 October 2018 at http://help.visionhealth.co.uk/Patient_Services_-_Patient_Help_Centre/v1.7/Content/C_FAQ/FAQs.htm)
- The Waiting Room (accessed on 10 October 2018 at https://thewaitingroom.net/TWR_Manual.pdf)

NHS England’s GP online services team offer materials for patients, including easy read leaflets (https://www.england.nhs.uk/gp-online-services/support/supporting-material/patient-information-guides/).

You can order promotional materials from NHS England (accessed on 10 October 2018 at https://www.england.nhs.uk/gp-online-services/support/supporting-material/order-materials-online/)

The RCGP Toolkit contains templates forms for signing up new applicants for Patient Online and proxy access and information leaflets on abnormal laboratory results.

Computer literacy and digital inclusion

The Good Things Foundation coordinate a network of learning centres where patients can boost their computer skills. Find your local centre at https://www.goodthingsfoundation.org/online-centres-network (accessed on 10 October 2018).