

# A professional's guide to online and proxy access to medical records for children and young people.

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## 1. GP online services, what are they? What are the benefits and the risks?

### 1.1 NHS App and your NHS account

An NHS account gives patients access to certain NHS services online. Patients can log into their NHS account using the NHS App or the NHS website.

The NHS App provides a simple and secure way for patients or their carers to access a range of NHS services on their smartphone or tablet. Anyone aged 13 or over and registered with a GP practice in England or the Isle of Man can download the NHS App on an iOS or Android device.

Those that do not have a device they can use to download the NHS App, or do not want to download it, can log into the NHS website as a quick and easy way to access their NHS account. Although the NHS still recommend use of the NHS App for the best user experience.

The NHS is working to make it easier for patients to digitally access their health information in their GP record so they can understand and manage their own health. Since December 2022, GP practices in England have started to enable their patients over the age of 16 to access **new** health record entries as part of a phased roll out. Patients will see new information once it is entered, or filed, onto their record in the clinical system. Patients will not see their historic, or past, health record information unless they have already been given access to it by their general practice.

### 1.2 What services can be accessed via NHS online GP services?

#### Partial Access to NHS App.

**Before proving who, you are, you can use the NHS App to:**

- Use NHS 111online to answer questions and get instant advice or medical help near you.
- Search trusted NHS information and advice on hundreds of conditions and treatments.

**You need to prove who you are to get full access to the NHS App. With full access you can:**

- Order repeat prescriptions and name a pharmacy where you would like to collect them.
- Book and manage appointments.
- View your GP health records and see information like your allergies, immunisations, and medicines from the date that access is granted. If your GP has given you access to your detailed medical record, you can also see information like test results and hospital letters.
- Book and manage coronavirus (COVID-19) vaccination.

### **1.3 What information cannot be viewed online?**

- Any data entered onto the consultation screen prior to the date online access was granted.
- Any data entered before the date that the patient registered with their current GP practice.
- Any data entered before the patient turned 16.
- Tasks and internal communication in practice (e.g., Emails, screen messages)

### **1.4 What are the benefits of online access to patients?**

Access to medical records encourages patient centred care. The patient is a member of the management team for their condition. A patient with access to their own health data can,

- better understand their own health,
- research their own conditions,
- have better ownership of their management and
- be more responsible for their health outcomes.

The patient may also be better enabled to monitor prescriptions, book, and cancel appointments all via the same platform, and to check results and referrals.

With appropriate consent carers and family members can be given access to interact with the medical record on the patient's behalf.

### **1.5 What are the possible risks?**

- GP records sometimes contain confidential information that relates to third party individuals which the patient must not see.
- Safeguarding risks can occur if a patient is coerced to share their online record access.
- The patient may fail to seek health care for fear of a lack of confidentiality.
- There may also be information that may harm the patient:
  - a diagnosis, abnormal result, or opinion that the patient is not aware of
  - records of a past traumatic event that might re-traumatise the patient.
  - jargon or language that means something different to the patient.

## **2. Children and young people GP online services guide**

### **2.1 Introduction.**

GP Online Services are particularly useful to carers and family members who have a child with serious or complex long-term conditions. Record access enables a better understanding of the child's health and health care and enables the child or young person and their parent / carer to be prepared for consultations and engage in decisions about care. In short, it facilitates a collaborative person-centred approach to the care of the child.

Data protection legislation states that young people may consent to have access to online services after their 13th birthday. Even after the birthday, the GP will decide whether having online access is in the patient's best interests and may refuse access if there are significant concerns that it may not be. Assessment of the young person's capacity to give informed consent and keep their access

private should be considered. It is appropriate for the GP practice to decline access if the patient lacks the capacity to consent or to keep their access secure.

If the practice considers that it is in the best interest of a young person under the age of 16 to have online record access, they will consider seeking the consent of someone with parental responsibility for the young person (see below for definitions of parent and parental responsibility), although legislation does say that "The consent of the holder of parental responsibility should not be necessary in the context of preventive or counselling services offered directly to a child" (recital 38, General Data Protection Regulation).

## 2.2 Definitions

For the purposes of this document, a parent refers to anyone who has legal parental rights and responsibilities for a child, and family is used to refer to any group consisting of one or more parents and one or more children.

Parental Responsibility is defined in s 3(1) Children Act 1989 as being:

*"all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property".*

The term 'Parental Responsibility' attempts to focus on the parent's duties towards their child rather than the parent's rights over their child. Someone with parental responsibility is responsible for, among other things, agreeing to the child's medical treatment. For Looked After Children carers may have delegated authority regarding medical treatment decisions.

## 2.3 Proxy access for children and young people

Before a child develops the capacity to make informed choices about their healthcare, including using GP Online Services safely, the usual position would be for someone with parental responsibility for the child to control access to GP Online Services. They may apply to the child's GP practice to have proxy access as a trusted third-party where it is in the child's best interest.

Where someone is seeking proxy access as a parent/ carer on behalf of their child, the practice will determine if they have parental rights (see above). The GP practice will also consider if a parent has no or limited legal right of access because they have been perpetrators of abuse and/or neglect.

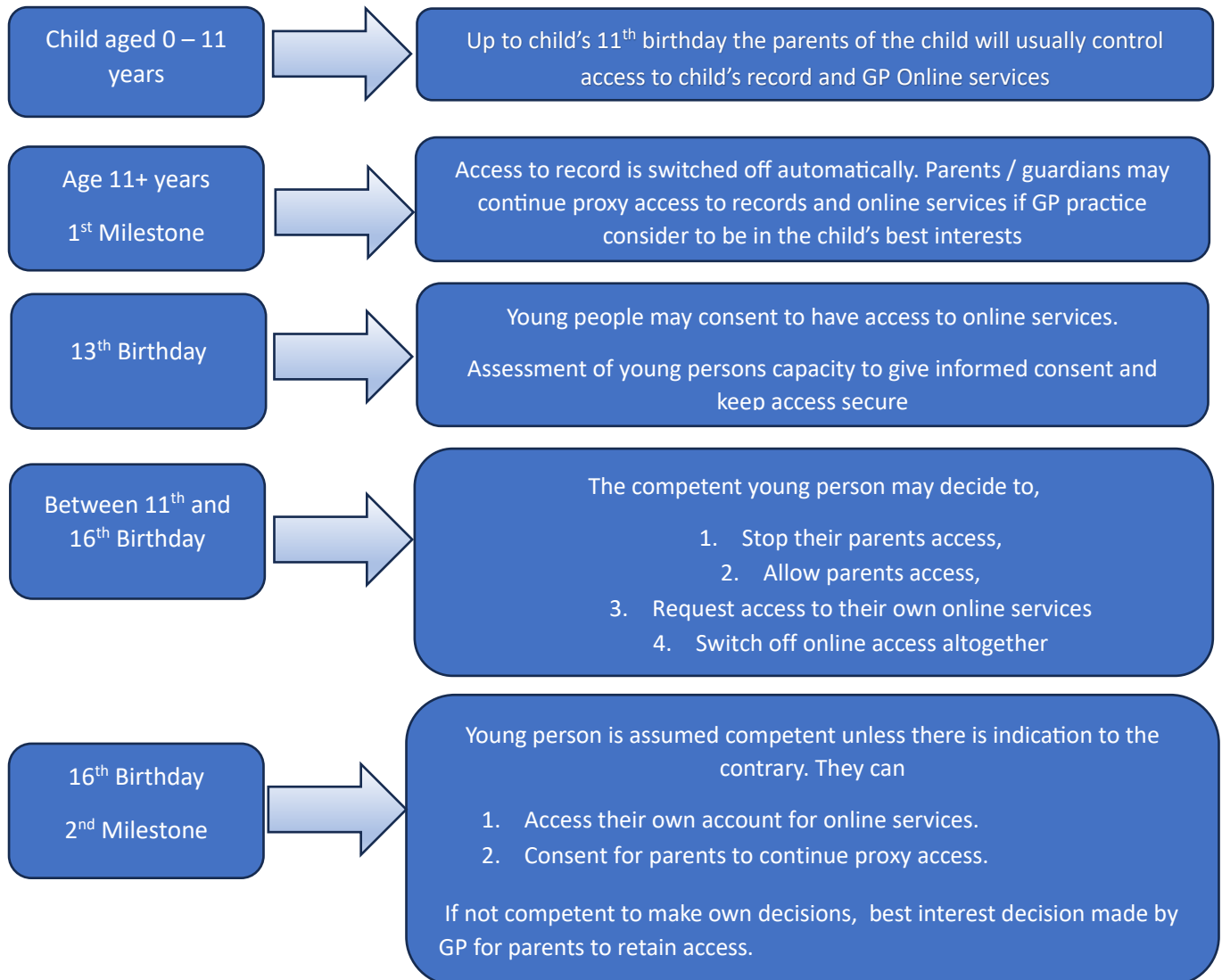
## 2.4 Safeguarding concerns about young people

An individual's safeguarding risk may fluctuate. It may arise in previously safe circumstances. Within the limitations of the consultation, it may be very difficult for a health professional to detect that a child has become at safeguarding risk. Health professionals need to be aware of the risks that parents may misuse proxy access in a way that is harmful to the child or to monitor their record for evidence that professionals suspect there are safeguarding risks.

Proxy access for a parent or carer must not inhibit entering information about safeguarding concerns in the child's record. A clear record of evidence or suspicions of abuse can be a vital factor in colleagues' later decisions about the safety of the child. Failing to record concerns could place the child at risk. All safeguarding information that is entered in the record in consultations, documents

or by any other route should be hidden from online view by the proxy or the child. This is known as redaction.

## 2.5 Competence assessments and milestones



### 2.5a Approaching a child's 11th birthday – The first milestone

Up until a child's 11th birthday, the parents of the child will usually control access to their child's record and GP Online Services.

Access to the record is switched off automatically when the child reaches the age of 11. This avoids the possibility of:

- Sudden withdrawal of proxy access by the practice alerting the parents to the possibility that the child or young person has been to the practice about something that they wish to remain private, an example may be family planning advice.

- The young person being deterred from coming to the practice for help.

Parents/Guardians may continue to be allowed proxy access to their child's online services, after discussion with the GP, if it is felt to be in the child's best interests.

The GP practice may contact parents or guardians who have proxy access for a child, who is approaching their 11th birthday, to remind them that their access on behalf of their child is coming to an end and to invite them and their child to come to the surgery for a discussion about the reasons why proxy access has been withdrawn.

### **2.5b Between the 11th and 16th birthdays**

Decisions made at the first milestone can be re-considered and changed later. Each case must be considered individually with the interests of the child being paramount. For example, for parents with GP online services access on behalf of children and young people with long term conditions that require regular monitoring and medication it would be appropriate for continued access after the 11th birthday, but this must be balanced against the challenges that may arise as the young person becomes competent to make their own decisions about their healthcare.

The young person may decide, once they are competent to act autonomously. Parental rights yield to the child's right to make their own decisions when they reach a sufficient understanding and maturity to be capable of making up their own mind on matters requiring decisions.

The age at which a young person becomes competent to make autonomous decisions about their healthcare, including who should have access to their GP online services, will vary from person to person. Where a parent, guardian or carer has proxy access to the online services of a young person after their 11th birthday, the child's competence to make an independent and informed decision about proxy access should be re-assessed regularly, perhaps on an annual basis or on request by the patient or the proxies. It may be possible to plan for proxy access to be withdrawn at some time in the future.

The competent young person may decide to:

1. Stop their parents' proxy access to their online services, where the parents still have access after the 11th birthday
2. Allow their parents to have access to their online services, or to allow limited proxy access to specific services, perhaps restricting proxy access to only book appointments or request repeat prescriptions
3. Request access to their online services where nobody currently has access
4. Switch off all online access, including parental proxy access, until such time as the young person chooses to request access.

### **2.5c Approaching a young person's 16th birthday - The second milestone.**

Once a young person turns 16, by default the previous competence assessment is no longer applicable as they are assumed to have capacity unless there is an indication to the contrary. If they

already have an account for GP Online Services, they will automatically have prospective record access. By default, they will have access to everything recorded in their notes from the start of the national programme for automatic record access in 2022. If they do not already have an account they can apply for one themselves at from their GP surgery.

Where parents or guardians still have access to their child's online services when the child reaches their 16th birthday, the proxy access should be reviewed.

- If the young person is not competent to make a decision about access at this age, for example if they have a severe learning disability, and it would be in the child's best interests for the parents to retain access, they may do so.
- If the young person consents for their parents to continue to have proxy access. It may be helpful to offer the 16-year-old their own personal GP Online Services account, following the usual protocols for identity verification, to reflect their new autonomy.

### 3. Looked After Children and GP online services.

#### 3.1 Proxy access

As mentioned above proxy access to GP online services may be particularly useful to foster carers, kinship carers and residential home staff caring for children and young people with long term medical conditions.

The health information held within the record belongs to the child, it is their personal and confidential information. Wherever it is possible to do so a discussion should take place with the child and their views regarding proxy access by the carer or care staff followed. If the child is unable to express their wishes where appropriate a best interest decision may be made. Where someone is seeking proxy access as a carer on behalf of a child, the GP practice will determine if they have parental rights or delegated authority for medical decisions (see above).

The proxy should be given their own online access account (rather than using the child's login details). Access given to authorised carers must be agreed between the:

- young person and / or their representative with parental responsibility.
- Foster carer, carer or residential home
- patient's GP practice.

Access is generally given from the date of moving into care, but longer, retrospective, proxy access can be given if the GP agrees this would be of benefit to the child or young person.

Proxy access should be reviewed as part of the placement planning process when a child enters, moves or leaves a placement. When a child is new to care following discussions with the social worker and where appropriate the child, carers with delegated authority for parental responsibility can apply directly to the child's GP practice for proxy access to the GP records. On leaving or moving placement it is the responsibility of the adult holding proxy access to inform the GP practice that they no longer have delegated authority for the child. A reminder of this should be provided by the social worker at the placement planning meeting.

### **3.2 LADO**

If a LADO enquiry takes place regarding a carer or care staff who have proxy access to medical records for a Looked After Child. The proxy access should be terminated and reinstated if required following the enquiry. The LADO should contact the GP practice directly to arrange for proxy access to be reviewed.

### **3.3 Online access 16+**

From the age of 13 young people can apply for online services. At the age of 16 they can apply to their GP practice for access to view all new GP consultations and medical documents through the NHS App. This would include access to letters and reports from the date that online access was granted. For Looked After children this may allow young people to directly access the health information in future health assessments and their care leavers health summary. The NHS App should be discussed at health assessments for all young people aged 15+.

### **3.4 Medical history and care leavers summary**

Statutory guidance states that care leavers should have a summary of all health records, including genetic background and details of illnesses and treatments, which suggest how they can access a full copy if required (Promoting Health 2015). On leaving care the young person will be given a care leavers health summary which will contain the health information gathered whilst the young person was in care. This is an important document which contains medical information that may be needed when applying for college, jobs, passports, visas etc. A copy of this document is held in the young person's GP record.

### **3.5 Ability to request full medical record.**

If a young person would like information regarding their previous medical history, they can request a full set of their medical records from their GP. The GP record is the central NHS record for the young person. The medical history will contain details that have been shared with the GP via other health professionals, the young person and their family. Information regarding third parties will be removed from the medical record before it is shared with a young person.

Details such as family history rely on family members sharing this with the GP or other health professionals. These may be missing from the medical record if details have not been shared with health professionals in the past. Wherever possible it is essential that medical information is collected from the parents by the social worker when the child comes into care. However, there may be situations where the medical history is not available to the social worker when the child becomes looked after. Past medical history should form part of the referral information for the initial health assessment. This information will then be included in the health summary sent to the GP following the initial health assessment.

When accessing health information, a young person may need help or support in interpreting the information provided or in reading records of past traumatic events. A social worker, carer, GP, health professional or other trusted adult may be required to provide this support. Where potentially information is held within the records the GP practice may ask a young person to come into the practice to discuss their medical record or may need to redact information regarding third parties.

## References

Promoting Health and Wellbeing of Looked After Children 2022

[NHS England » How proxy access works](#)

[Proxy Access.docx \(live.com\)](#)

[Children and young people.docx \(live.com\)](#)