CHILDREN AND YOUNG PEOPLE

Patient Online is particularly useful to families who have a child with serious or complex long-term conditions. Booking and cancelling appointments at the practice and ordering prescriptions are convenient and less prone to mistakes. Record access enables a better understanding of the child’s health and health care and enables the child or young person and their parents to be prepare for consultations, and engage in decisions about care. In short it facilitates a collaborative person-centred approach to care of the child.

People aged 16 or above are assumed to be competent to make an independent and informed decision about whether to ask for someone to have proxy access to their GP online services and record, unless there is an indication that they are not. Children vary in the age at which they develop capacity to make an independent and informed decision about their health care, confidentiality and who should have access to their record.

Data protection legislation states that young people may consent to have access to online services after their 13th birthday. The practice must still make a decision about whether having access to Patient Online is in the patient’s best interests and may refuse access if there are significant concerns that it may not be or if the patient lacks the capacity to consent or to keep their access secure.

If you consider that it would be in the best interests of a younger child to have their own Patient Online account you should consider seeking consent of someone with parental responsibility for the child (see below for definition of parent and parental responsibility), although the 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).

Definitions
For the purposes of this document, a parent is used 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.

All mothers and most fathers have legal rights and responsibilities as a parent - known as parental responsibility. Someone with parental responsibility is responsible for, among other things, agreeing to the child’s medical treatment. A parent who does not live with the child still has a right to be kept updated about their well-being and progress. Circumstances surrounding who has parental responsibility may be complicated, therefore access should be granted on a case by case and with advice from a medical defence body.

Proxy Access for children and young people
Before a child develops the capacity to make informed choices about their healthcare or Patient Online, or to be able to keep their Patient Online account secure, the usual position would be for someone with parental responsibility for the child to control access to their child’s record and online services and to have proxy access where it is in the child’s best interests (see the Proxy Access guidance in the toolkit).

Practices should be mindful of the benefits of proxy access for children and families, whilst also protecting the small number of children and young people who could be at serious risk of harm from their family if medical information (such as use of the contraceptive pill) is inadvertently disclosed.

The practice may receive requests for proxy access to book appointments, order repeat prescriptions or access the GP record on behalf of a child or young person. If the child does not have the capacity to consent to proxy access, the decision has to be made by the practice based on what is thought to be in the child’s best interests. The decision should usually be taken by the GP who knows the child and family best. It may be helpful to consult practice team members and other health and care professionals who know the family well.

Where someone is seeking proxy access as a parent on behalf of their child, care has to be taken to determine if they have parental rights (see above).
Care must also be taken if a parent has no or limited legal right of access because they have been perpetrators of abuse and/or neglect.

If an abuser becomes aware that abuse has been detected, the risk of harm to the child is increased. If proxy access has been granted to a parent or carer, it must not inhibit recording of safeguarding concerns. Failing to record concerns could place the child at risk because information may not be available to other health professionals involved with the child. The information must be recorded and redacted so that it is hidden from online display. If your GP system functionality does not allow such data to be hidden, it may be prudent to refuse or withdraw parental access to children’s records.

**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 online services.

Access to the detailed care record should be switched off automatically when the child reaches the age of 11. This avoids the possibility of:

1. 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, or
2. The young person being deterred from coming to the practice for help.

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

A practice may want to contact parents 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.

**Between the 11th and 16th birthdays**

Decisions made at the first milestone can be reconsidered and changed later. Each case must be considered individually with the interests of the child being paramount. For example, parents with online access on behalf of children and young people with long term conditions that require regular monitoring and medication may have a good case for continued access after the 11th birthday but this must be balanced against the risks 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 mature enough to act autonomously. The decision about the capacity of young people can be complex. In particular learning difficulties may not be well documented. It may also be difficult to identify coercion of a young person to allow parental or carer access. Parental right yields to the child’s right to make their own decisions when they reach a sufficient understanding and intelligence to be capable of making up his own mind on the matter requiring decision. (Gillick or Fraser? A plea for consistency over competence in children, BMJ 2006;332:807).

The age at which a young person becomes competent to make autonomous decisions about their healthcare, including who should have access to their online services, will vary from person to person. Where a parent or carer has proxy access to the online services of a young person after their 11th birthday, the patient’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, such as appointment booking or repeat prescription requests, but not to the medical records
3. Request access to their online services where nobody currently has access
4. Switch off all online access until such time as the young person chooses to request access.

**Approaching a young person’s 16th birthday - the second milestone**

Once a young person turns 16, the previous competence assessment by default is no longer applicable as they are assumed to have capacity unless there is an indication to the contrary.
Where parents still have access to their child’s online services when the child reaches their 16th birthday, the parents’ access should be reviewed.

1. 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.

2. 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 Patient Online account, following the usual protocols for identity verification, as a marker of their new autonomy.

Where a young person has already been given control over access to their online services before their 16th birthday, and their parents do not, there is no need to make any changes unless the young person wishes to do so.

Safeguarding concerns about young people
Young people living in certain circumstances such as within an extended family or institutions such as children’s homes or care homes may have no opportunity to view their records in conditions of privacy. Similarly, patients who are illiterate in English might be forced to use family members as interpreters, as is currently the case with consultations in certain ethnic communities. In such circumstances Patient Online creates new safeguarding risks.

It may be very difficult for a health professional to detect coercion within the limitations of the consultation, for example in cases of sexual exploitation where a young girl may be accompanied by her pimp posing as a concerned boyfriend. Practices are advised to exercise caution and refer to the Coercion Guidance in the toolkit.

Further reading
- Parental rights and responsibilities, UK Government
- Protecting children and young people: The responsibilities of all doctors, General Medical Council
- Children and young people ethics tool kit, British Medical Association
- Safeguarding Children Toolkit for General Practice, Royal College of General Practitioners
- Confidentiality and children, Medical Defence Union