DH Department of Health

Consent – what you have a right to expect

A guide for children and young people

Consent – it's your choice

Before a doctor, a nurse, or anyone else looking after your health can examine you or treat you, did you know they need your *consent*? That means they must get your agreement. Choosing whether to give consent needs thinking about. This leaflet is your guide to:

- *how* consent is asked for and given;
- *what* you need to know before giving consent;
- *how* old you should be to give consent on your own;
- *when* your parents can be involved;
- *when* other people can give consent for you;
- *what* to do if you're asked to help with research.

How will you be asked?

The way doctors and nurses ask for consent partly depends on what they plan to do. They may ask in an informal way, that is, without asking you to say anything but simply to do something.

For example, they might ask to have a look at your throat. If you then open your mouth, it's a signal that you consent.

For something more complicated, like an operation, you'll be asked directly – for example to sign a form agreeing to the treatment.

What do you need to know before giving consent?

In order to make a decision, you and your parents need the doctor or nurse to give you information about the treatment which they are offering. You should always ask questions if you don't understand or feel you want to know more. For instance, you might want to find out about:

- why they think the treatment will be good for you;
- what sort of things it will involve;
- what benefits they hope will result;
- how good the chances are of you getting such benefits;
- whether there are any alternatives;
- whether there are any risks;
- whether the risks are small or large;
- what may happen if you don't have the treatment.

If the person who is asking you to give consent to the treatment isn't able to answer your questions, ask them to find out or arrange for someone else to talk to you about your concerns.

How long can you take to decide?

If you want time to think about your decision, say so. In emergencies, decisions may have to be taken quickly, perhaps to save your life. But at other times it is often possible to take as much time as you need.

When can you give consent for yourself?

Always if you're 16-18 years old

You can give consent to being examined or treated in the same way that adults can. If you agree to a particular treatment, the doctor or nurse does not have to ask your parents for consent as well. But if you decide to refuse a particular treatment, sometimes your parents may get involved (see page 7).

Sometimes if you're under 16

If you are under 16, you may still be able to give consent for yourself – provided you're able to understand what is involved in the proposed treatment.

This means that you may be able to agree by yourself to some treatments, investigations or immunisations, and not to others. For example, if you're 13 or 14, you may be able to give consent yourself for an injection to protect you against meningitis. However, the information needed for agreeing to something as serious as a heart operation might be too much to weigh up by yourself.

When should your parents play a part?

Even if you *are* able to give consent yourself, it's still a good idea to include your parents in your decision. If they know what is happening, they will be able to help you think through your decision and to support you better. That is why doctors, nurses and other people caring for you will encourage you to involve your parents. If you are close to other adults, such as your grandparents or an aunt, you might like to involve them too.

What if you don't want your parents to know?

Sometimes young people want to be able to get advice or treatment, such as contraception, but may not want to tell their parents. If you are able to agree for yourself, the doctor or nurse will not tell them without your permission except in exceptional circumstances to protect you or someone else from serious harm.

When can other people give consent for you?

If you're under 18 and you find it too difficult to decide or you feel you don't understand enough, other people can give consent on your behalf. Usually this will be:

- your parents or guardian if you are living with them *or* being looked after by the local authority with the agreement of your parents;
- either your parents or your social worker if you are under a care order.

What if you don't want to consent but your parents do?

The rules say that your parents may still decide that it is in your best interests to have a particular treatment, and give their consent on your behalf. This rule applies until you reach the age of 18. However, it is exceptional for a disagreement to get this far without being sorted out.

In very serious or complicated situations, **a court** can be asked to decide whether it is right for your doctor to go ahead with a particular treatment. This might happen, for example, if you and your parents disagreed over whether you should have a very serious operation.

Sometimes you may be asked to take part in research. What then?

The research project may be part of your treatment, for example, to compare two different kinds of treatment; or it may be quite separate, such as providing additional blood samples. If it is separate, you can expect that the project would only have a very small effect on you and would not be against your interests. A research project will always be approved by a Research Ethics Committee before you are asked to take part in it.

You should be given an information sheet with details about the research, and you should ask as many questions as you want about the research. These could cover:

(for all kinds of research)

- the purpose of the research;
- any possible risks;
- how great or small the risks might be;
- any possible benefits;

(and if the research is a new or different treatment)

- what the standard treatment would be;
- any possible alternatives.

If you don't like the idea, you can always say no. Or you can talk it over with your parents before deciding. Saying no should not affect the rest of your care in any way.

Are there any advantages or disadvantages to agreeing?

Research is needed because doctors don't have all the answers. The doctor may suggest that a new trial treatment might benefit you, but there may be unknown risks. If, after considering all the potential risks and benefits, you don't want to take avoidable risks by taking part, you don't have to. All treatments, even established ones, have risks and these have to be weighed up when making your decision.

Remember, if you decide you don't want to be involved, you are entitled to say no. You will still be able to have the available standard treatment.

Suppose I'm not happy about how I've been approached about consent?

You can tell the health care professionals concerned that you're worried. But if you're still not satisfied, you are entitled to complain. You or your parents can find out how to go about it from *Your Guide to the NHS* or from NHS Direct on 0845 4647. NHS Direct can also give you details of a new service called PALS (Patient Advocacy and Liaison Service) designed to help sort out problems simply and quickly.

Would you like more help with giving consent?

Here's a list of useful organisations which you can ask for more help and support about giving consent and taking part in research.

The Patients Association

Address: P.O. Box 935, Harrow, Middlesex, HA1 3YJ
Telephone: Helpline 0845 6084455; Office 020 8423 9111
Fax: 020 8423 9119
Website: www.patients-association.com
Provides a helpline, information and advisory service and publications; campaigns for a better health care service for patients.

Patient Concern

PO Box 23732, London SW5 9FY
Phone/fax: 020 7373 0794
Email: patientconcern@hotmail.com
Website: www.patientconcern.org.uk
Provides patient leaflets and a patient advisory service specialising in consent-related issues; campaigns for patient choice and empowerment.

CERES (Consumers for Ethics in Research)

Address: P.O. Box 1365, London N16 0BW
Email: info@ceres.org.uk
Website: www.ceres.org.uk
Produces leaflets, *Medical research and you* and *Genetic research and you* for people considering taking part in medical research.

Health websites (with lots of links to other useful sites):

www.lifebytes.gov.uk
(for 11-14 year olds)
www.mindbodysoul.gov.uk
(14-16 year olds)

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