



PATIENT INFORMATION SHEET FOR CHILDREN AGED 6–10 YEARS

What children need to know about our project

1.

We would like you to read this with your mum or dad.

The doctors and nurses can also help you.

You are invited to join a big science project.

It is for children who are ill and their family. It is also for children who have been ill before.

Ask your mum and dad or the doctors and nurses if you have any questions.

2.

Some grown-ups and children get ill.

Then doctors and nurses look after you and your family. They also work with scientists to find out why we get ill.



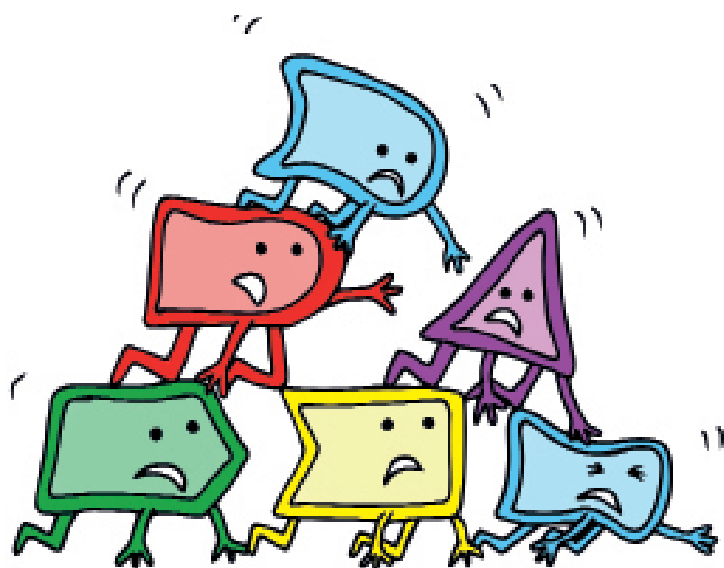
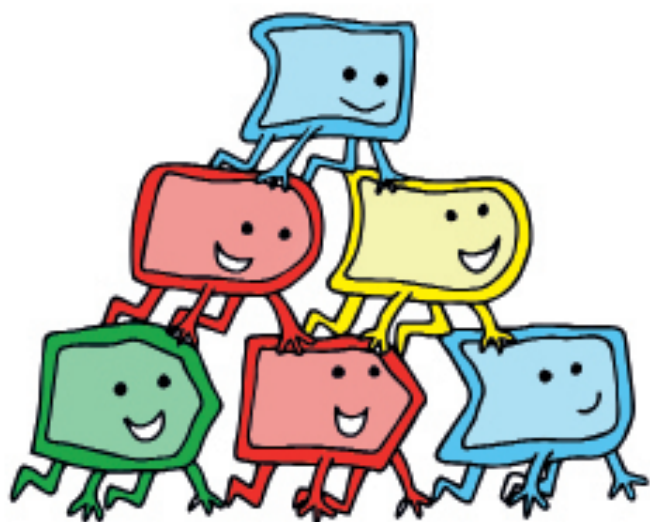
Genes in our bodies tell our bodies what to do. This is like when you bake a cake and you use a recipe.

Genes tell our bodies how to keep us healthy. But sometimes things go wrong.

Like if you put the wrong thing in the cake and it doesn't turn out how you expected.

We need to find out more about how our genes work.

Then we will be able to stop more people getting ill. And we may find ways to make them better when they do get ill.



4.

Why me?

We are asking boys and girls who have been ill to take part in a science project.

And we may ask their brothers and sisters to take part too.

This is to help us understand why some children get ill and others don't.

5.

What will I have to do?

You can help by giving us a small amount of your blood.

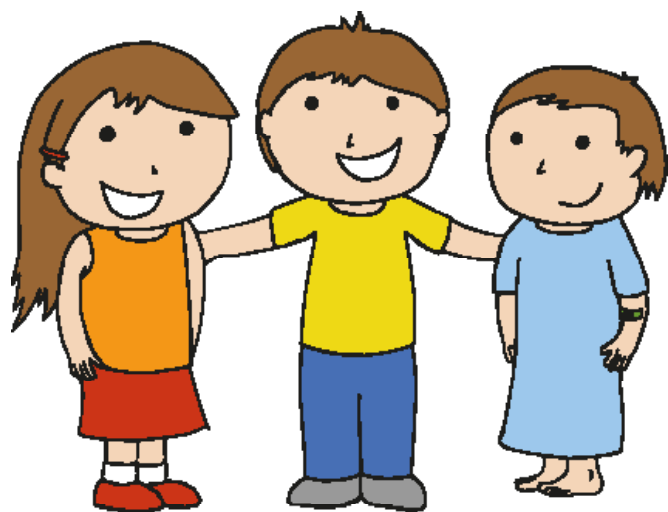
We would really like to use blood for the tests.

But if we can't take your blood for any reason, we will use spit (saliva) instead.

We will explain how we take the blood.

It will hurt a little bit.

But we can put some cream or spray on your arm to make sure it hardly hurts at all.



6.

Where will I give my blood or saliva?

A doctor or a nurse might collect your blood at the hospital.

This could be when you or your family have their next visit.

Or we might be able to visit you at your house.

Your mum or dad can stay with you when we collect the sample.

7.

What will you do with my blood?

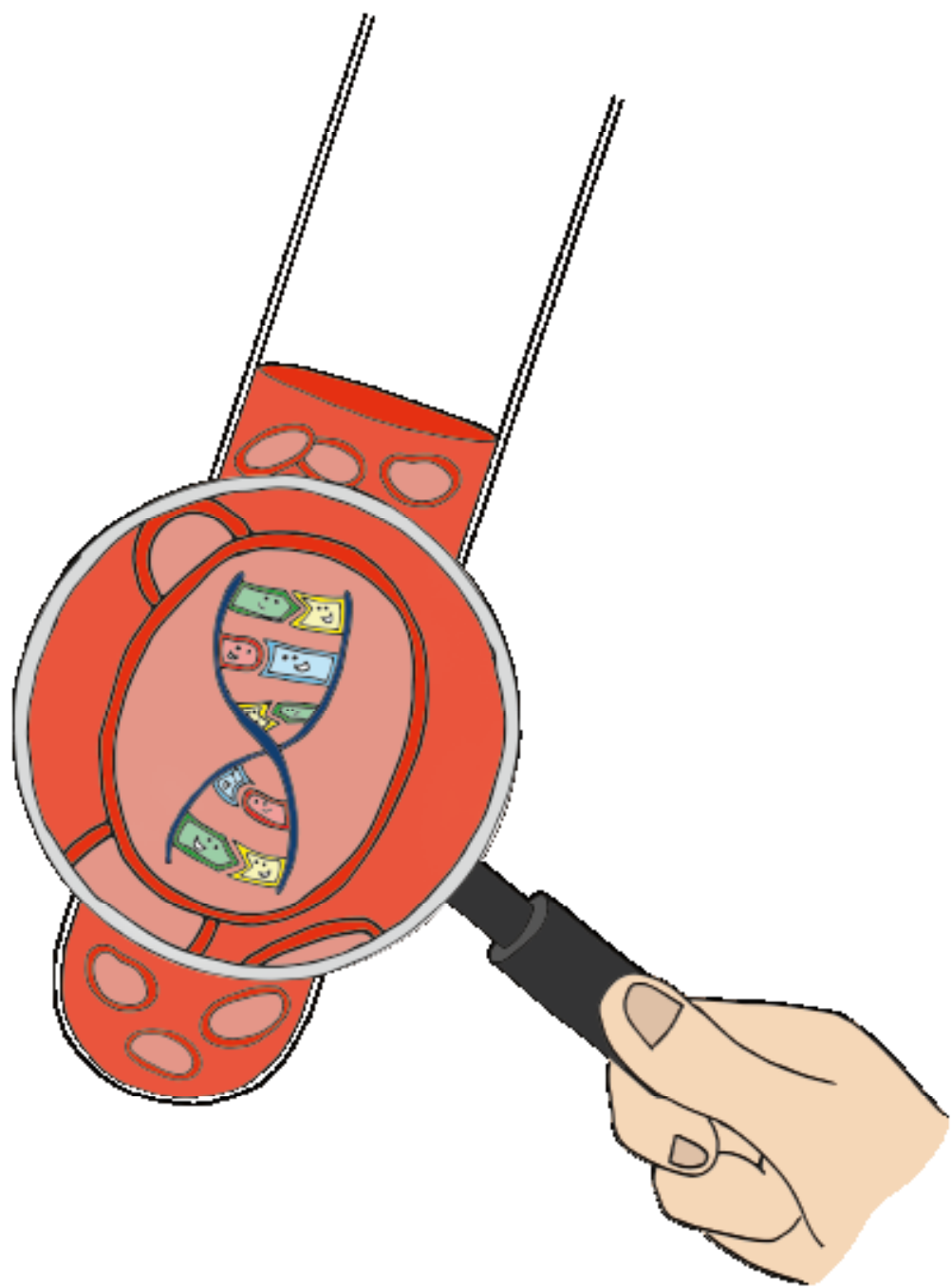
There are very small building blocks in your body called cells.

We will get some of your cells out of your blood.

The cells are so small you can't even see them.

We need to get your body's recipe out of your cells.

Then we need to look at what it tells your body to do.



Why is it good for me to take part?

We may find out things that could help you or your family. But if we don't, we could still find out things that help other people in families just like yours.





Do I have to take part?

You and your mum and dad should talk about it. If together you decide not to take part, that's OK.

Your family does not have to be in the study. And none of you will get into trouble.

But your parents, doctors and nurses may think it's important that you do take part. That's because they think it might help you and your family in the future.

If there are things that you are worried about, talk to your parents and the doctors and nurses. Tell them how you feel.

After you talk to them, your parents will decide if you should join or not.

10.

What will happen next?

We may ask you if you want to take part in more science projects in future.

We won't ask you very soon. But might ask you again when we would like to know more.

If we ask you again, we will tell you and your family all about what we are doing so you know if you want to take part.

11.

Will anyone else know I am doing this?

Your family and your doctors and nurses will know you are taking part. Some people from the project will also know you are taking part. But no one else.

You can talk to anyone you want about the project. You can ask any questions you have. But we won't tell anyone else you are taking part.

If you decide to help then your blood sample will have a special number.

The scientists who will look at it will not know who you are. They will only know the number.

12.

What if I don't want to take part anymore?

It's OK if you join the project and then change your mind and want to stop.

Tell your mum or dad or the doctors and nurses if you want to stop.

Your parents will decide if you should stop or not after you tell them how you feel.

13.

If I say 'yes' - what happens next?

If you say 'yes' then you will be asked to sign a form.

Your mum or dad will also have to sign a form.

This means that they allow you to take part.



14.

A long way ahead!

When you are 16 years old we will ask you again if you still want to take part in this study.

You will be old enough then to decide for yourself. So it will be up to you.

**Thank you for reading this –
please ask any questions.**

INSERT LOCAL CONTACT
DETAILS/
LABEL HERE