

Department of Clinical Biochemistry

Collection of blood spots for the home monitoring of Phenylketonuria (PKU)

Information for parents and carers

Introduction

This leaflet aims to give you information on home monitoring, blood spots and taking blood samples.

What is home monitoring?

This is when a blood sample is taken at home and sent to the laboratory to monitor Phenylalanine levels.

What is Phenylalanine and who needs to have it measured?

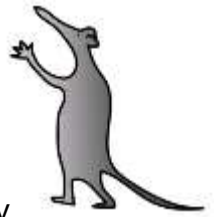
Phenylalanine is a natural part of all protein foods, but it accumulates in children and adults with Phenylketonuria (PKU). The level of phenylalanine can be controlled by a special diet, but blood samples need to be taken to make sure the level of phenylalanine is not too high or too low.

Why do we do it?

So we can monitor dietary control without you having to make lots of hospital visits.

What happens?

- Blood samples are taken onto filter paper and posted to a laboratory in Alder Hey.
- The blood samples are analysed daily in a batch of other blood samples.
- The Dietitian will ring you with the results and give advice on your child's diet.



Are there risks in taking a blood sample at home?

There is a slight risk of infection at the pin prick site to reduce this risk please ensure you child's finger/heel is clean before you prick it. If the finger/heel becomes red or inflamed please seek medical advice.

There is always a small risk of infection from blood borne viruses when taking blood samples. This risk can be reduced by washing your hands before and after taking blood or wearing disposable gloves.

If you spill blood clean it up as soon as possible with hot water and disinfectant.

Keep all sharps in a safe place and dispose of them in a sharps container.

When the sharps container is full close it securely and bring it back to Alder Hey for disposal.

Are there any alternatives?

The only alternative would be to come to Alder Hey more frequently to have the blood sample taken.

What will happen if tests are not taken?

We may not be aware that your child's phenylalanine levels are high. High levels of phenylalanine in the blood are harmful to the brain. If dietary control is poor, schooling and behaviour can be affected and your child may not achieve as much as they are capable of.

Will it hurt?

You'll need to make a small pin prick in your child's finger or heel, so it can hurt them just a little.

How to take a good blood sample at home

Preparation

- Take blood samples at the same time of day each week, (morning samples are best if possible). Give yourself plenty of time to take the sample. Have a relaxed environment such as a comfortable chair or a bouncer seat for a baby. If blood is being taken from a baby's heel you may want to lie them down on a change mat.
- Get the equipment together. You will need:
 - A sample card labelled with a **name sticker** or complete the boxes with: **name, date of birth and Alder Hey number if known**. Please check the expiry date on the back of the card before use and contact the Dietetic department if your cards are about to expire. We are unable to analyse samples on cards past their expiry date.
 - A PKU Home monitoring sticker filled in with the **date and time the sample was taken** and whether your child is **well or ill**.
 - An alcohol wipe.
 - A lancet.
 - Kitchen roll.
 - Sharps disposal container.
- Wash your hands.
- Warm the hand or heel from which blood is to be taken.
- Babies less than 4 months old should have blood taken from their heel. Older children should have blood taken from their finger.
- Don't take blood from the same place each time; choose a different finger or heel.



Taking the blood sample

- Clean the warm finger/heel with the alcohol wipe (if your child's hands are very dirty wash them with soap & water first).
- Hold the lancet to the finger/heel and press the button. (The back of the collection card shows safe heel puncture sites, blood can be taken from the fleshy area at tip of finger).
- Allow blood to flow to the puncture site by releasing pressure and holding hand/heel down.
- Gently squeeze and release to allow a large drop of blood to form (this might take a few squeezes).

- Catch the blood drop on the filter paper card.



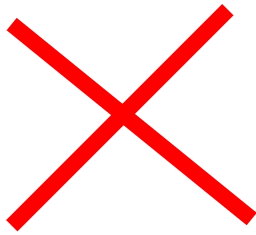
- Please fill at least two circles as shown below.



- Blood spots need to be big enough to fill the circle and soak through the card.



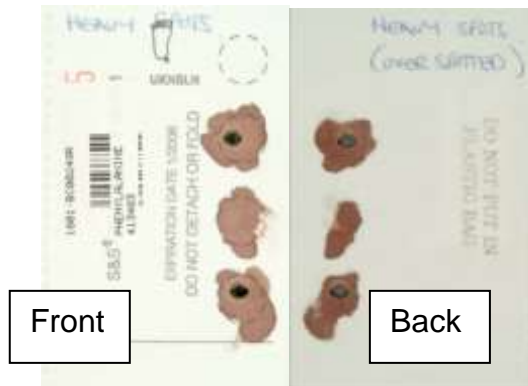
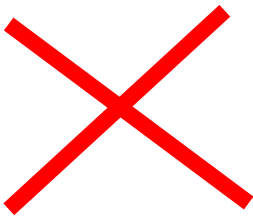
- **Do not** put very small spots on the card. Continue to squeeze and release the finger /heel until a larger drop of blood has formed.



These spots are too small.

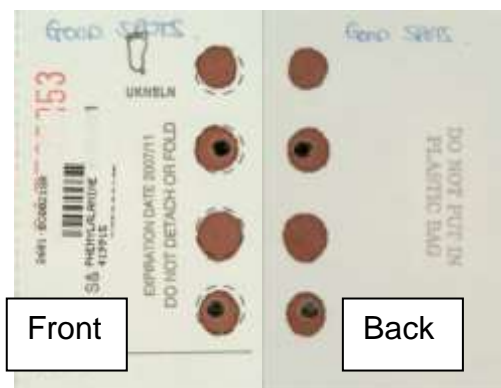
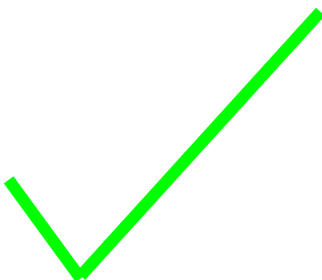
The blood has not soaked through to other side of filter paper.

- **Do not** put more than one large drop of blood in each circle (this will lead to a falsely increased result!).



There are too many drops of blood on each circle here.

The Phenylalanine result from this sample may be higher than it should be!



These blood spots are perfect!

Once the blood sample is taken:

- Safely dispose of the lancet by putting it in a sharps container.
- Wash your hands.
- Allow the blood spots to dry naturally - do not place on direct heat e.g. hairdryer, radiator etc.

- Check that correct **name & sample date & time** details are on the card. Tick if your child is well or ill.

IMPORTANT – If your child’s name is NOT on the sample we will NOT be able to analyse it!

- If you need name labels please ask for them (see the telephone numbers below).
- Place sample card (spots first) in the waxy cover, this can be done while the spots are still moist.
- **Do not** place sample in plastic bag as it will not dry properly.
- Post the sample as soon as possible to the address below using the pre-addressed envelopes supplied:

The Metabolic Section, Biochemistry Department
 Alder Hey Children’s NHS Foundation Trust
 East Prescott Road
 Liverpool
 L14 5AB



Further Questions

If you would like some lessons on taking blood samples:

Please ask the phlebotomists when you come to have blood taken for your next clinic appointment.

If you require more labels, filter papers, envelopes or lancets:

Please ask for them when you attend clinic or contact the Dietitians on 0151 252 5876 / 252 5231 if you are not due to attend clinic for a while. You can also email pk@alderhey.nhs.uk

If you require another sharps disposal container:

Contact your doctor (GP) for further supplies or ask the phlebotomists when you come to clinic. Bring your full sharps bin back to Alder Hey for disposal or contact your local council.

If you have any problems:

Please contact Allyson Terry on 0151-252-5876 or email pk@alderhey.nhs.uk

Departments to contact for further information or advice:

Department of Clinical Biochemistry Tel. 0151-252-5486
 Department of Dietetics Tel. 0151-252-5231

This leaflet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child's treatment.

This information can be made available in other languages and formats if requested.

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