



# **Alström Syndrome UK**

Strength for today, hope for the future

**Highly specialised multi-disciplinary clinics for  
children and adults diagnosed with Alström Syndrome**

## Introduction

NHS England commission highly specialised clinics in Birmingham for children and adults who are diagnosed with Alström Syndrome. There are only a small number of people diagnosed with Alström Syndrome in the UK, these centres of excellence have been established to develop expertise and to support and advise patients, their families and their local health, education and social care service providers.

Alström Syndrome UK (ASUK) works in partnership with the clinical teams and regularly gathers feedback from patients to continually develop and improve the clinics. ASUK help to coordinate the clinics, can provide overnight accommodation if needed and offer support.

## Children's Specialised Service

Children's clinics are held in Waterfall House at Birmingham Children's Hospital, outside view pictured right.

Birmingham Children's Hospital,  
Steelhouse Lane, Birmingham, B4  
6NH

Telephone Number: 0121 333 9267

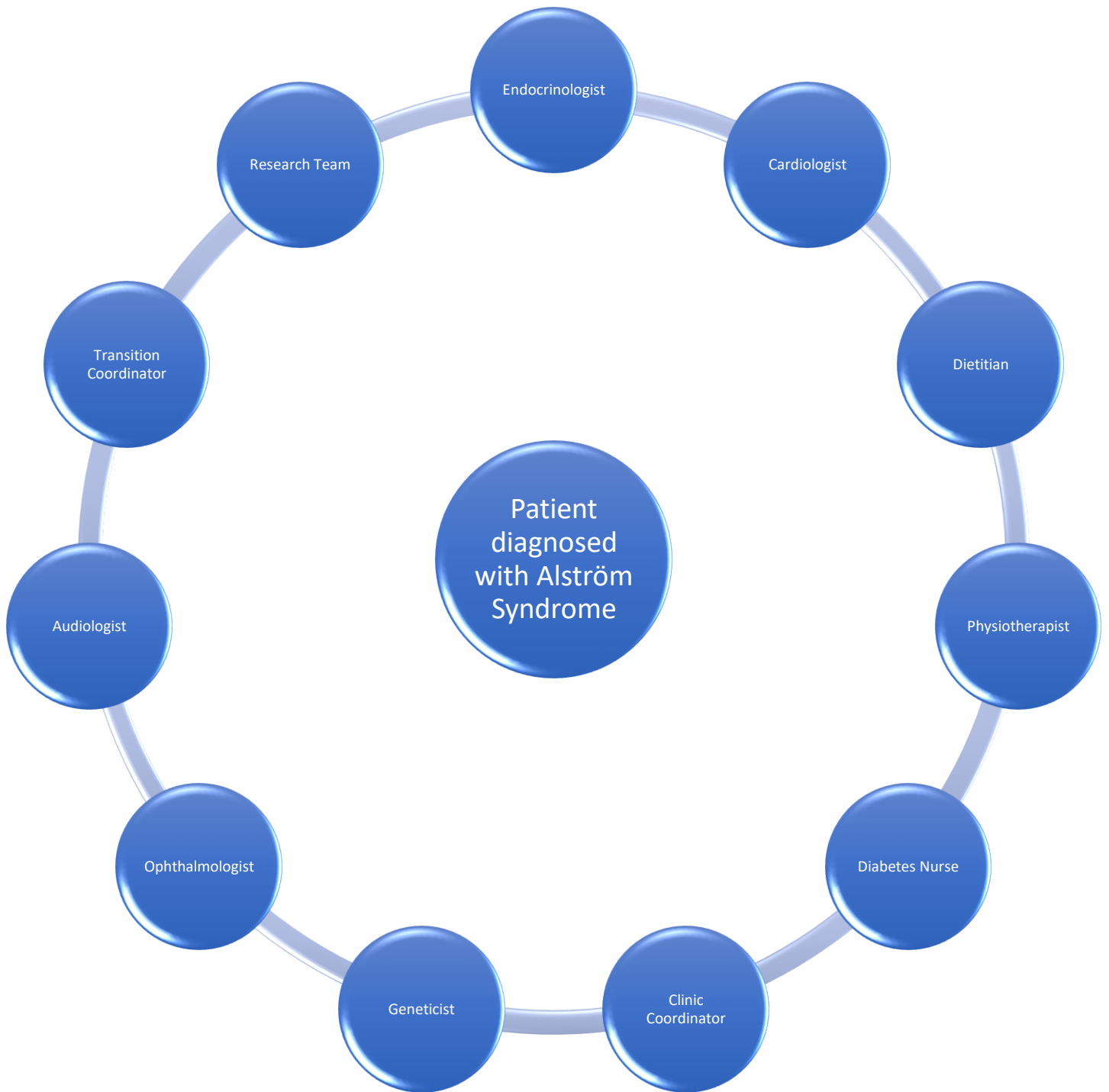
Hospital directions can be found via  
this link <https://bwc.nhs.uk/waterfall-house/>



Birmingham Children's Hospital provide support to children and young people up until the point they are ready to move onto the adult service, usually between the ages of 16 to 18. There are several specialists involved in the clinical service and tests are carried out to help monitor and manage the condition. Tests and consultations take place throughout one full day and accommodation can be provided in the evening, before clinic, in a nearby hotel.

Generally, young people are reviewed once a year unless an alternative review date is necessary. The results of the tests are discussed with young people and their parents during the clinic, where possible, other results are sent by post along with a clinic summary letter and management plan. A copy of this summary letter is sent to their local GP and any other specialist involved (with the young person and parents' permission). Some travel expenses can be claimed for those in receipt of certain benefits – please see appendix 1.

# Specialists at the Children's Clinic



Clinical Lead at the children's clinic:  
Professor Timothy Barrett, Paediatric Endocrinologist.



## Tests to expect at the Children's Clinic

Height and Weight	All young people are weighed and measured at the beginning of each clinic to monitor their growth.
Blood Pressure	A blood pressure cuff is placed around the arm and it will inflate and become tight. This measures the pressure that your heart uses to pump blood around the body. Occasionally, young people may be asked to keep this on to measure blood pressure over 24 hours.
Urine Test	Young people are asked to collect a urine sample on the morning of clinic, to monitor how the kidneys are working. This will be monitored yearly.
Blood Tests	A blood test will be carried out at clinic. Cream or spray will be provided if needed to help numb the area. Blood tests are used to monitor a variety of different things and a full list of the tests can be found in the Alström Syndrome Handbook which is provided by the hospital.
ECG	This can also sometimes be called a heart trace and it is used to measure the rhythm and electrical activity of the heart. Stickers, called electrodes are placed on different parts of the body and wires are connected to them and to a machine to give a reading. The test is quick and painless.
Echocardiogram	This is a type of ultrasound scan that looks at the heart and the vessels around it. Jelly is placed on the chest and a probe is then used to create images. This is a painless test, but young people will need to lie still for around 30 minutes.
X-rays	Sometimes an x-ray will be done if a young person is suspected to have a chest infection or to look at their bone age. Bone age is used to predict height and helps to assess the maturity of the bones, which can be used to assess the stage of growth of a young person.
FibroScan	This is an ultrasound scan of the liver which can detect fibrosis or fatty deposits. Jelly will be placed on the skin and a probe uses high frequency sound waves to identify any inflammation. This is a painless test, but some young people may find it a little uncomfortable. Not all young people will have this test as part of the clinic and it is usually only done with teenagers or where blood tests suggest a scan is required.
Eye Tests	Can be carried out if required, but it is not an essential part of the clinic if the young person and their parents feel they

receive good local support. If tests are required, then eye drops will be used to dilate the pupils to see and take photographs of the back of the eye. The drops can sting a little and eyes can become more sensitive to the light for a brief period.

## Hearing Tests

Can be carried out if required, but it is not an essential part of the clinic if the young person and their parents feel they receive good local support. If tests are required, then an audiogram will be done which measures whether a person can hear a range of different sounds.

## Adult Specialised Service

Adult Clinics are held in the Centre for Rare Diseases at the Queen Elizabeth Hospital in Birmingham, pictured right.

Heritage Building, Queen Elizabeth Hospital, Mindelsohn Way, Edgbaston, Birmingham, B15 2TH

Telephone Number: 0121 3716984



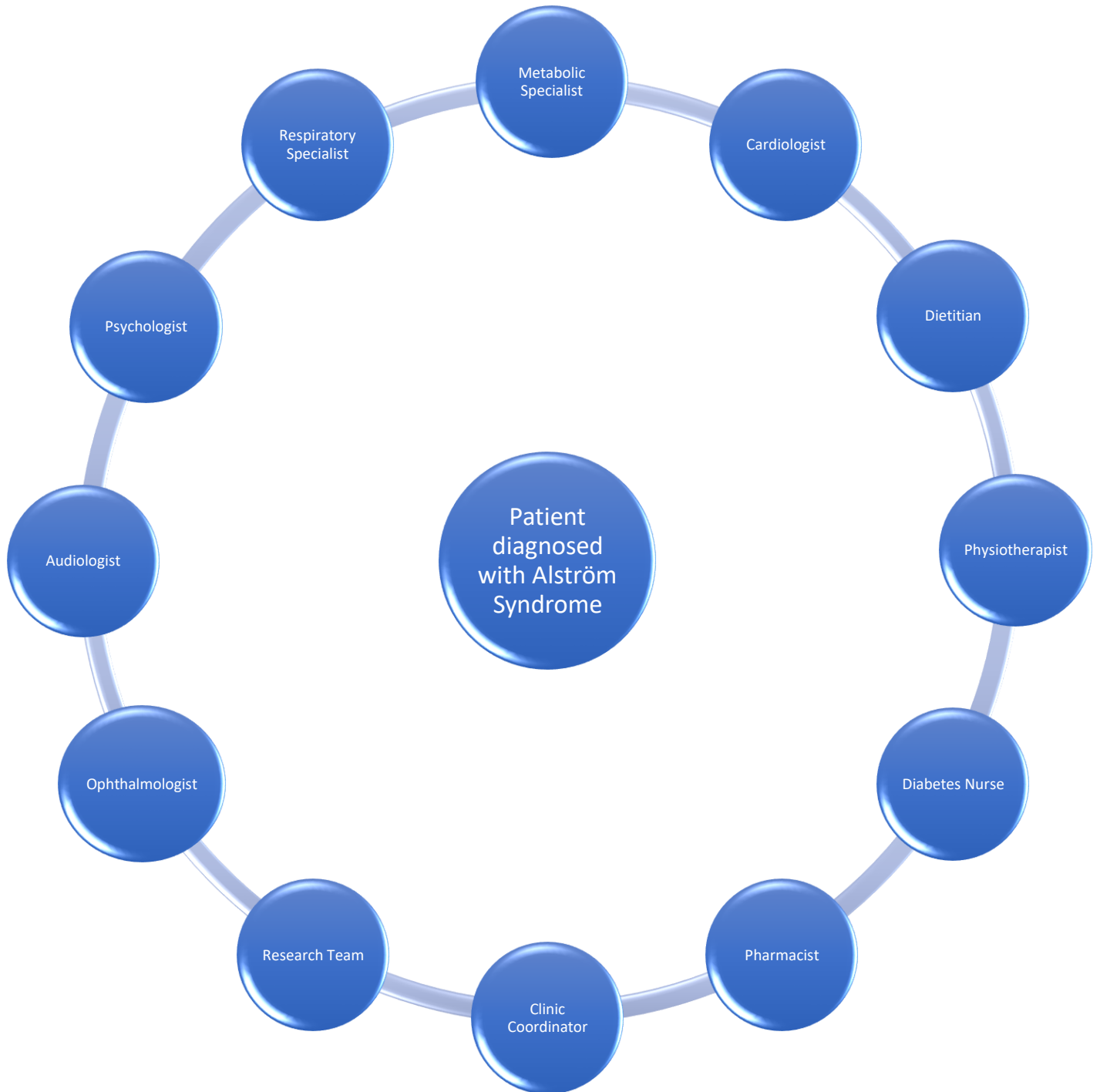
Hospital directions can be found via this link  
<https://www.uhb.nhs.uk/how-to-find-us-crd.htm>

The clinics for adult patients take place within the Centre for Rare Diseases at the Queen Elizabeth Hospital, Birmingham. There are several specialists involved in the service and a range of tests are carried out to help monitor and manage the condition. Tests and consultations take place over two or three days (depending on availability) and accommodation can be provided in a nearby hotel.

Adult patients are generally reviewed annually unless an alternative review date is necessary. The results of the tests are discussed with adult patients during the clinic, where possible, and other test results are sent by post along with a clinic summary letter and management plan. A copy of this summary letter is sent to the local GP and any other specialist involved (with the patient's permission).

Some travel expenses can be claimed for those in receipt of certain benefits – please see appendix 2.

# Specialists at the Adult Clinics



Clinical Lead at the Adult clinic:  
Dr Tarek Hiwot, Consultant in Inherited Metabolic Disorders



## Tests to expect at the Adult Clinics

Height and Weight	All patients are weighed and measured at the beginning of each clinic to monitor their growth.
Blood Pressure	A blood pressure cuff is placed around the arm and it will inflate and become tight. This measures the pressure that your heart uses to pump blood around the body. Occasionally, patients may be asked to keep this on to measure blood pressure over 24 hours.
Urine Test	Patients are asked to collect a urine sample on the morning of clinic, to monitor how the kidneys are working. This will be monitored yearly.
Blood Tests	A blood test will be carried out at clinic. Cream or spray will be provided if needed to help numb the area. Blood tests are used to monitor a variety of different things and a full list of the tests can be provided.
ECG	This can also sometimes be called a heart trace and it is used to measure the rhythm and electrical activity of the heart. Stickers, called electrodes are placed on different parts of the body and wires are connected to them and to a machine to give a reading. The test is quick and painless.
Echocardiogram	This is a type of ultrasound scan that looks at the heart and the vessels around it. Jelly is placed on the chest and a probe is then used to create images. This is a painless test, but patients will need to lie still for around 30 minutes.
FibroScan	This is an ultrasound scan of the liver which can detect fibrosis or fatty deposits. Jelly will be placed on the skin and a probe uses high frequency sound waves to identify any inflammation. This is a painless test, but some may find it a little uncomfortable.
Eye Tests	Can be carried out if required, but it is not an essential part of the clinic if the patient receives good local support. If tests are required, then eye drops will be used to dilate the pupils to see and take photographs of the back of the eye. The drops can sting a little and eyes can become more sensitive to the light for a brief period.
Hearing Tests	An audiogram will be done which measures whether a person can hear a range of different sounds. Hearing aids will be checked to ensure they are suitable, and the Audiologist will examine the ears to make sure they look clear and healthy.

Lung Function Test	These are breathing tests that are carried out to check how well the lungs are working. This will involve blowing into a machine and following instructions to hold your breath and to blow out at different speeds and for different lengths of time. Some adult patients find this test quite difficult, but it is painless.
Cardiac MRI	This is used to create detailed images of the heart and blood vessels. Hearing aids will need to be removed for this test, but headphones are provided, and someone will give clear instructions to hold your breath at regular intervals. The test lasts around one hour.
CT Angiogram	This test uses x-rays to provide detailed images of the heart and blood vessels. A cannula is placed in the arm and a dye is injected. You may need to have a tablet to lower blood pressure before having this test and the dye will not be used on patients who have poor kidney function. Although some adult patients find cannula's uncomfortable, the test itself is painless, although the medication can make you feel hot or like you need to pass urine.
Abdominal Ultrasound	Jelly is placed on the abdomen and a probe is then used to create images of the liver, gallbladder, spleen, pancreas, and kidneys.
DEXA Scan	This test uses low dose x-rays to take measurements to work out the strength (density) of the bones.

## General Information

### Clinic Letters

The hospital will send you a letter before clinic to confirm the date and time of your appointment. You will also receive a letter from ASUK to confirm your accommodation booking if required.

After the clinic, a summary letter will be sent out to you, your GP and your local hospital specialists explaining your test results and management plan.

### Support at Clinics

A member of ASUK's Family Support team will be available at each clinic to provide additional support. However, we advise that all patients are accompanied to, during and from the clinic by a family member, support worker or advocate.

Be prepared that there is often lots of waiting around to see different specialists at clinics and some tests will take place in different parts of the hospital. Someone will be available to make sure you get to where you need to be.



All children must be accompanied by a parent or carer and we advise parents to bring some toys for children to play with, that will help to keep them occupied.

We recommend that siblings do not attend clinic appointments.

Lunch and refreshments are provided during clinics and there are canteens and cafes where you can purchase additional items.

## Clinic Evaluation Forms

ASUK will provide you and your family member/carer with a clinic evaluation form and we ask that you complete the form in as much detail as possible. All comments and suggestions are used to share feedback with the hospital teams and NHS England as we aim to continually improve the service. Please tell any of the ASUK team if you have concerns, complaints or compliments!

## Contact Details

### Birmingham Children's Hospital

Directions: <https://bwc.nhs.uk/travel-information>

Administration Coordinator: Lindsay Wilson: 0121 333 9267

Medical Advice: Professor Timothy Barrett via hospital switchboard: 0121 333 9999

### Queen Elizabeth Hospital, Birmingham

Directions: <https://www.uhb.nhs.uk/how-to-find-us.htm>

Administration Coordinator: Liz Wadsworth - 0121 3716984

Medical Advice: Dr Tarek Hiwot – 07979 127826

### Alström Syndrome UK

Registered Office: 4 St Kitts Close, Torquay, Devon, TQ2 7GD

Website: [www.alstrom.org.uk](http://www.alstrom.org.uk)



#### Office Manager

Catherine Lewis

Email: [catherine.lewis@alstrom.org.uk](mailto:catherine.lewis@alstrom.org.uk)

Telephone: 07970 071675 / 01803 368871



#### Senior Family Support Worker

(for patients living in the South of England): Jane Biglin

Email: [jane.biglin@alstrom.org.uk](mailto:jane.biglin@alstrom.org.uk)

Telephone: 07714 798413



#### Senior Family Support Worker

(for patients living in the Midlands & North of England): Carrol Birchall

Email: [carrol.birchall@alstrom.org.uk](mailto:carrol.birchall@alstrom.org.uk)

Telephone: 07847 760467



#### National Development Manager / Family Support Manager

Kerry Leeson-Beevers

Email: [kerry.leeson@alstrom.org.uk](mailto:kerry.leeson@alstrom.org.uk)

Telephone: 01709 210151 / 07716135940

## **Appendix 1 Information provided by Birmingham Children's Hospital**

### **Healthcare Travel Costs Scheme**

If you are in receipt of one of the following benefits you are entitled to claim for travelling costs for appointments for NHS treatment. These can be claimed at the Cashier's Office. Please note that payment cannot be made by Cashiers without production of the relevant documentation detailed below. However, postal claims can be made by completion of a HC5 form.

1. Income Support
2. **Income Based** Employment Support Allowance
3. **Income Based** Job Seekers Allowance
4. Low Income HC2 or HC3 Certificates
5. Tax Credits **with** an exemption certificate
6. Pension Credit **Guarantee** Credit
7. Universal Credit – if earnings are within the stated guidelines detailed in your most recent assessment letter (dated within 2 months of your appointment)

### **What Documents do I need to Claim Travelling Expenses?**

- Proof that you are in receipt of one of the above benefits (dated within 12 months except item 7 above)
- Appointment letter or card
- Bus/Train ticket

### **How are the Travel Costs Calculated?**

Patients travelling on public transport will be reimbursed for the lowest cost form of public transport (including any promotional or concessionary fares)

Patients travelling by private car may claim the lesser of, mileage allowance or equivalent public transport costs.

### **Claiming for Taxi or Escort Costs**

These costs may only be paid where deemed medically necessary in writing by your GP, Consultant or other health care professional involved in your care. Please note that escort costs will be paid on the basis of your eligibility not that of the escort. There are forms available from the Cashier's Office for this purpose.

### **Exclusions**

Visiting a patient in hospital is not covered by this scheme.

Patients who discharge themselves from hospital at their own request.

Private Patients

### **Cashier's Office Opening Hours**

Monday – Friday 9am – 1pm & 2pm – 4.30pm

Closed – Weekends and Bank Holidays

- ❖ The Cashiers Office is near to the main hospital entrance, next to the Birmingham Children's Hospital Charity Shop

## **Appendix 2 Information provided by the Queen Elizabeth Hospital, Birmingham**

### **Healthcare Travel Costs Scheme**

If you are in receipt of one of the following benefits you are entitled to claim for travelling cost for appointments for NHS treatment. These can be claimed at the Cashier's Office. Please note that payment cannot be made by Cashiers without production of the relevant documentation detailed below. However, postal claims can be made by completion of a HC5 form.

1. Income Support
2. **Income Based** Employment Support Allowance
3. **Income Based** Job Seekers Allowance
4. Low Income HC2 or HC3 Certificates
5. Tax Credits **with** an exemption certificate
6. Pension Credit **Guarantee** Credit
7. Universal Credit – if earnings are within the stated guidelines detailed in your most recent assessment letter (dated within 2 months of your appointment)

### **What Documents do I need to Claim Travelling Expenses?**

- Proof that you are in receipt of one of the above benefits (dated within 12 months except item 7 above)
- Appointment letter or card
- Bus/Train ticket, parking ticket/receipt, Tax receipt if applicable

### **How are the Travel Costs Calculated?**

Patients travelling on public transport will be reimbursed for the lowest cost form of public transport (including any promotional or concessionary fares).

Patients travelling by private car may claim the lesser of, mileage allowance or equivalent public transport costs.

### **Claiming for Taxi or Escort Costs**

These costs may only be paid where deemed medically necessary in writing by your GP, Consultant or other health care professional involved in your care. Please note that escort costs will be paid based on your eligibility not that of the escort. There are forms available from the Cashier's Office for this purpose.

### **Exclusions**

Visiting a patient in hospital is not covered by this scheme.

Patients who discharge themselves from hospital at their own request.

Private Patients.

### **Cashier's Office Opening Hours**

Monday – Thursday 9am – 4.30pm

Friday 9am – 4pm

Closed – Weekends and Bank Holidays

- ❖ The Cashiers Office is in the main Queen Elizabeth Hospital building, before ambulatory care on the ground floor