

Transcranial Doppler Ultrasound Scan Local Guideline, Stroke Screening for children with sickle cell disease in Newham.

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Version Control Summary

Version	Date	Author	Status	Comment
1	14/11/2013	Sekayi Tangayi	Service Manager/ Specialist Nurse	Revised- Newborn Screening & Care of children with Major Haemoglobin disorders- Screening operational Policy
2	14/04/2015	Sekayi Tangayi	Service Manager/ Specialist Nurse	Revised- Newborn Screening & Care of children with Major Haemoglobin disorders- Screening operational Policy
3	30/10/2019	Sekayi Tangayi	Service Manager/ Specialist Nurse	Revised- Newborn Screening & Care of children with Major Haemoglobin disorders- Screening operational Policy
				The original version of this document is in version 1 and 2 above.
				2020 has now been split to ensure the quantity is minimised and also due to variations in the subject matter. This document will only address local pathway for Transcranial Doppler Ultrasound Scan, Stroke Screening for children with sickle cell disease in Newham.

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1.1 Introduction

Sickle cell disease is known to be associated with a high risk of children developing a stroke in the early years of childhood. Research shows that risk of a secondary stroke can be significant and the only way this can be prevented is through treatments such as chronic blood transfusions and a drug called hydroxyurea.

Sickle cell disease is an alteration in the gene that provides instructions to build the oxygen-carrying protein in red blood cells. This alteration leads to the formation of sickle-shaped red blood cells. Because of their abnormal shape, these red blood cells tend to get trapped inside small blood vessels and cause them to become narrower. The narrowing of blood vessels in the brain increases the risk of stroke.

A stroke is when the blood vessels are narrowed to the extent that parts of the brain are no longer sufficiently supplied with oxygen and nutrients. A stroke damages the brain and may cause difficulties in talking, understanding what is said, remembering things, and paralysis or numbness of the hands and feet or face. Also a stroke is a medical emergency which needs prompt treatment and if left untreated the more brain damage can occur

Around the site in the brain where the blood vessel is narrowed by sickle-shaped red blood cells, the blood travels faster. This can be measured by a test called Transcranial Doppler Ultrasound Scan (TCD). A study called The Stroke Prevention Trial in Sickle Cell (STOP) showed that TCD is useful in identifying patients at high risk of stroke. Recommended protocols for TCD originate from this study. Eleven percent of sickle cell patients have a stroke by the age of 20, and the risk is highest between ages 2 and 16 years.

This document must be read in conjunction with the following standards:

Transcranial Doppler Scanning for Children with Sickle Cell Disease Standards and Guidance

Second Edition UK September 2016

NHS Sickle Cell and Thalassaemia Screening Programme. Public Health England Sickle cell disease in childhood: standards and guidelines for clinical care 2019

Their Contact -

And

Public Health England, Wellington House, 133-155 Waterloo Road, London SE1 8UG

Tel: 020 7654 8000 www.gov.uk/phe

Twitter: @PHE_uk Facebook: www.facebook.com/PublicHealthEngland

Standards for the clinical care of children with Sickle Cell disease will be found on the Sickle Cell Society website,

Their contactTel: 020 8961 7795 / 020 8961 8346info@sicklecellsociety.org Address - Sickle Cell Society, 54 Station Road, London NW10 4UA

1.1 Purpose

This is part of the national screening care standards. The service is for all children from the age of 2 to 16 years with a diagnosis of sickle cell disease with genotypes such as HbSS or HbS/beta zero thalassaemia. The aim of screening is to identify and monitor children who are high risk of developing strokes.

2.1 Stroke Screening

Stroke screening is intended to identify children with sickle cell disease who are at a high risk of developing an actual stroke. The risk is not the same for all children with sickle cell disease and it is most relevant for children with HbSS and HbS/beta thalassaemia zero.

The clinic is run at the Sickle Cell & Thalassaemia Centre on a Saturday to improve accessibility and to allow parents and children access to out of hours cares. Newham is currently the only trust in England that has successfully arranged this test in the community as an out of hour's service in order to meet the needs of the local community.

3.1 The aim of the screening is to:

- 1. Identify children with high Doppler's, from the ages of 2 to 16 years old.
- 2. Monitor them and organise further investigations if needed.
- 3. If there is evidence of stroke, treatment with regular blood transfusion or hydroxyurea will commence.

4.1 Entrance Criteria:

- 1. Age 2 to 16 years old.
- 2. Children with a confirmed diagnosis of Sickle Cell anaemia HbSS.
- 3. Children with a confirmed diagnosis of Sickle Cell Disease HbSBeta Thalassaemia Zero.

5.1 Exclusions:

- 1. All children with confirmed carrier results (HbAA, HbAS, AC, AD, AE, OArab etc).
- 2. All children with inconclusive haemoglobinopathy screening results.
- 3. All children with unusual benign haemoglobins (haemoglobinopathies).
- 4. All children with other Sickle Cell diagnosis such as HbSBeta Thalassaemia plus, HbSC, HbSD, HbSE etc. .

1.2 What is Transcranial Doppler Ultrasound Screening?

Transcranial Doppler ultrasound scan (TCD) is a test that uses ultrasound to measure the velocity or speed of blood flow through the blood vessels in the brain. It serves as a predictor for the risk of stroke.

2.2 How is TCD performed?

The TCD scan takes about 15 minutes and is non-invasive. The speed of blood flow through the blood vessels in the brain is measured from outside with an ultrasound probe, similar to ultrasound scans that are performed during pregnancy.

3.2 What happens after the scan?

If the scan looks normal with a blood velocity below 170 cm/s, the scan is called standard and the scan is repeated in one year.

If the measured velocity of blood flow is between 170 cm/s and 200 cm/s, the scan is referred to as conditional, and it is recommended that it be repeated within 4 weeks to three months.

With a velocity above 200 cm/s, the scan is abnormal is called Standard Risk and should be repeated within one week to confirm the result. The result might also be confirmed by magnetic resonance angiography (MRA), a non-invasive exam that allows checking the blood vessels in the brain in more detail.

In the case of an abnormal scan, the doctor might order a blood transfusion with red blood cells or start hydroxyurea, decreasing the viscosity of the blood and reducing the risk of stroke.

4.2 Results Coding:

Results -	Meaning	Follow up
Normal	low chance of having a stroke	1 year
Conditional- risk	medium chance of having a stroke	3 to 6 months
Abnormal- Standard Risk	high chance of having a stroke	4 weeks,
Limited	could not take all the pictures to identify Risk	Needs MRI scan

1.3 Process for clinic follow up:

1. Children are generally referred from Newham University Hospital; within the local existing data base of affected children or Bart's and the London paediatric clinic.

- 2. Clinics occur once per month on a Saturday, and are run by the Outreach Consultant Haematologist from the Clinical Network Centre Royal London Hospital.
- 3. All appointments are booked 1 year in advance and all appointments are booked with the parent before leaving the clinic and they are issued with an appointment letter.
- 4. As stated above if the child results were not normal and the child needs to be seen sooner than a year then the appointment is booked with the parent before they leave and an appointment letter is issued.
- 5. All parents are called a week prior to clinic to remind them and then 2 days before the clinic. This is also followed up with a text reminder.
- 6. On the day the administrator calls all parents and confirms that they are definitely coming, if not their appointments are rescheduled on the phone.
- 7. The specialist nurse and clerical administration team prepares a list of children who are due to have yearly Doppler screening and maintains a master list on a spreadsheet which is shared with the hospital staff.
- 8. All appointments are booked via RIO.

2.3 On the day of the appointment the specialist carries out an assessment to identify the following:

- 1. Date of last crisis?
- 2. Any problems at school or home?
- 3. Last hospital admission?
- 4. Any diagnosis of sleep apnoea?
- 5. If child is on Hydroxyurea?
- 6. Any child protection issues?

3.3 Documentation of visit and results:

- 1. All documentation is done on RIO
- 2. The specialist nurse will inform the GP in writing and send information to Paediatric Haematology Clinic at Newham University Hospital and share all results in a timely manner.
- 3. Specialist nurse will co-ordinate treatment and further investigations if and when required such as hydroxyurea, blood transfusion and request MRI scans if not already organised.
- 4. The Consultant Haematologist will issue results a week post scans and the specialist nurse will process the results.
- 5. The responsibility of the administrators is to chase up results from the patient co-ordinator from Royal London hospital and ensure that the results are filed on Ndrive and on the patient file on RIO.
- 6. The administrator will notify Lead specialist nurse of the results and put on the specialist nurses' diary.

4.3 Clinic Cancellation by the parents:

If the parent cancels the clinic appointment the administrative team should check:

- a. The reason for cancellation and document on RIO progress notes, cancellation MUST be done via clinic rather than scratch pad.
- b. If the parents are refusing to attend TCD, the nurse MUST be informed and contact the parent and advice them appropriately and take appropriate actions if there are any safeguarding concerns.
- c. The parents' earliest convenience for re-booking the clinic appointment MUST be agreed whilst the client is still on the phone, and reschedule.
- d. If the parent cancels a 1st and 2nd appointment then, the specialist nurse write to parents and inform consultant haematologist, consultant paediatrician, service manager and GP.
- e. The specialist nurse can carry out an unannounced home visit and identify if there are any safeguarding concerns and take appropriate actions.

5.3 All children who were not brought for appointment (WNB) should be followed up:

- 1 Administrator to contact the parent by telephone to enquire reason for nonattendance within **30 minutes** of non attendance.
- 2 Check that another appointment has been set for the child.
- 3 If the child WNB for 2nd appointment then a letter and a leaflet MUST be sent to highlight the importance of regular follow up care.
- 4 An opportunistic home visit MUST be organised, but this may be problematic if the child attends school.
- 5 If the 3rd appointment is not attended then social services should be informed as this is a child safeguarding issue and child to be discussed in the Multidisciplinary meeting (MDT).
- 6 GP MUST be informed of non attendance in writing.
- 7 Non attendance should be documented on the RiO records.
- 8 Children with sickle cell disease or thalassaemia major syndromes should never be fully discharged from clinic without a thorough investigation of the reason for non-attendance

1.4 Monitoring Clinical Governance

Failsafe-

- 1 All referrals received must be accompanied with a confirmed diagnosis. Results notification is usually via nhs.net and uploaded to RIO. If no results to confirm diagnosis, the child will be put in general clinic for screening.
- 2 The administrator must acknowledge all email notifications and failure will result in a completion of a Datix. The referral must be filed in the appropriate files on nhs.net and Ndrive.

- 3 A nurse must check the referral and document in RIO progress notes.
- 4 All missing results or incorrect details identified must be followed by a Datix
- 5 NB- We do not offer repeat testing to confirm a diagnosis unless there is clear indication that one is required such as confirmatory testing or if there was an error with the sample. If unsure, to discuss with the specialist lead nurses/service manager in the 1st instance or the Laboratory who will discuss with the haematologist in the weekly multidisciplinary team meetings.
- 6 All Datix should be recorded on the local team spreadsheet and discussed at team meetings for learning purposes.

2.4 Incident Reporting

- a) All incidents related to the affected children TCD pathway must be reported via Datix and shared with the hospital teams.
- b) Incidents MUST also be reported using the national incident form to National Patient Safety Agency. (Form is on PHE quality assurance website) by the service manager if there is a need for an SUI (serious untoward incident). This should only be done after discussion with the specialist lead nurse/service manager who will inform the service director and the director of nursing and governance quality assurance teams.
- c) Incidents must also be reviewed locally by using the Trust agreed pathway for investigation and reporting.

3.4 The purpose of incident reporting is to:

- a) Review all incidents and apply the lessons learned.
- b) Use the incidents to inform an improvement in services.
- c) Use the incidents to support national and local policy development.
- d) Use the incidents to support development of national and local training resources.

References

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Appendix 1 - Parent Leaflet.

Transcranial Doppler Ultrasound Scanning for Children with Sickle Cell Disease in Newham – Information for parents:

Transcranial Doppler ultrasound is a test that uses sound waves to see the inside of the body. You will hear the staff at the Newham sickle cell center call it a "TCD or Dopplers." This test shows how fast blood moves through the blood vessels in your child's brain.

Why does my child need a TCD?

When your child has sickle cell disease, she has a higher risk of having a stroke than other children. A TCD checks your child's risk of a stroke. All children with sickle cell anemia (HbSS) or sickle beta thalassemia need this test starting at age 2. TCDs can help the doctor learn if there are:

- Objects blocking normal blood flow, such as clots, and
- Blood vessels that are getting narrow.

Both these things raise your child's risk of a stroke. So a TCD is important to learn your child's risk.

How is a TCD done?

A nurse or doctor who is trained to do TCD does this test. If you or your child had regular ultrasound before, TCD works the same way. The test uses a small probe that records images of the blood flow inside your child's head. The images show how well blood is flowing through the blood vessels.

How should my child get ready for a TCD?

Your child should wear comfortable, loose-fitting clothing and take off any hats or glasses. Hair clips and earrings might need to be taken off in areas where the nurse or doctor does the test. Your child can eat and drink normally before the test.

What happens during my child's TCD?

Your child lies on her back on an exam table. The nurse or doctor puts a clear gel on your child's head. This helps the ultrasound probe work better on the skin. The gel might feel cold at first. The nurse or doctor will wipe it off when the ultrasound is over. Next, the nurse or doctor presses the ultrasound probe firmly on your child's skin. The nurse or doctor might move the probe back and forth in a certain place, or press more firmly in some places. This helps get the best measurement of how blood is moving. During the exam, your child needs to:

Be awake,

Lie still, and

Be as quiet as possible.

Your child cannot eat, drink, or suck on a pacifier during the exam. If your child has trouble lying still or being quiet, you can bring their favorite toy or the specialist nurse can come in assist with keeping the child still and use distraction techniques.

Who sees the results and how do I get them?

The Consultant Haematologist who is trained to understand TCD and other imaging tests will report the results first and inform you on the day. The Consultant Haematologist will look carefully at how fast blood is moving through your child's brain. Then the Consultant Haematologist will send a report to the Lead Sickle Cell Specialist nurse and the Consultant Paediatrician who care for your child's sickle cell disease.

What do the results mean?

Below is a list of the possible results and what each one means.

Normal—your child has a low chance of having a stroke. She/he will have another TCD in one (1) year, or sooner if the sickle cell Consultant Haematologist thinks it is needed. The result will be in the clinic summary sent to the specialist Nurses who will send this report to the GP. An appointment will be given before you leave so remember to wait or ask for this.

Conditional—your child has a medium chance of having a stroke. She/he needs another TCD in 3 to 6 months, or sooner if the sickle cell Consultant Haematologist thinks it is needed. The Consultant Haematologist will talk to you about your child's stroke risk and whether treatment or further investigation is needed on the day of the test. An appointment will be given before you leave so remember to wait or ask for this.

Abnormal—your child has a high chance of having a stroke. She/he needs another TCD in 4 weeks, depending on what the sickle cell Consultant Haematologist decides. The Consultant haematologist will talk to you about your child's stroke risk and whether treatment or further investigation is needed on the day of the test. An appointment will be given before you leave so remember to wait or ask for this.

Limited—The Consultant Haematologist could not take all the pictures needed to learn your child's stroke risk. So your child's stroke risk is not known. If this happens, the Consultant Haematologist will tell you at the exam. Your child's sickle cell doctor will tell you when your child can have another TCD or require a different test.

What are the benefits and risks of TCD?

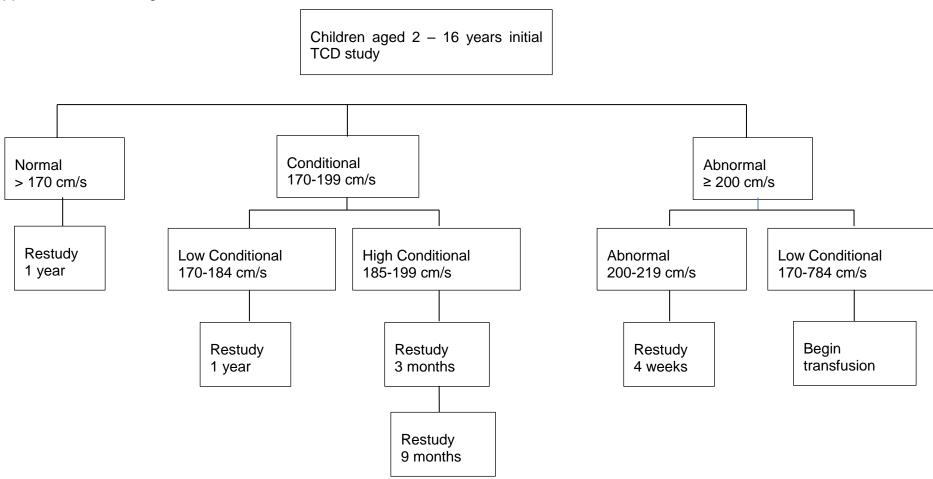
Benefits

- Ultrasound gives a clear picture of your child's blood vessels.
- Ultrasound is extremely safe. It does not use radiation.
- A TCD does not go inside the body. It does not use needles.
- An ultrasound might be uncomfortable for a short time, but it almost never hurts.
- Risks
- TCD does not have any harmful effects.

Questions? -

If you have questions about your child's TCD, please talk to your child's doctor or Lead Specialist nurse.

Appendix 2 Results Algorithm



TCD (non-imaging) blood velocity action limits and follows up protocols for sickle cell children aged between 6 and 10 years. (Time-averaged maximum mean blood velocities) The action limits could be 10% lower when using TCD to allow for the reported differences between imaging and non-imaging techniques.

Appendix 3

Useful contacts

Provider	Address	Name	Contact Number	Email
Clinic :	Sickle Cell and	Sekayi Tangayi – Lead	T: 02088210800	□group
East London Health Foundation Trust –	Thalassaemia Centre, 19- 20 High Street South, East	Specialist Nurse	M: 07908194497	elt-tr.sickleandthal@nhs.net or
Community Health Newham – Sickle Cell and Thalassaemia Team	Ham, E6 6EN ► Trust HQ, 9 Alie Street, London, E1 8DE	Administrator-Nillofeh Mahamadally	T: 02088210800	elt-tr.sickleandthal@nhs.net
Results : Bart's Healthcare Royal London Hospital	The Royal London Hospital 4th floor, Pathology & Pharmacy Building	Consultant Haematologist- Dr Paul Telfer	Mob:07906311482	Paul.Telfer@bartshealth.nhs.uk
	80, Newark Street, Whitechapel, E1 2ES	Secretary-Luke Shakleton Haemoglobinopathy	Tel: 0203 246 0352 –	luke.shakleton@nhs.net
			Fax :0203 246 0351	
		Network/Coordinator David Kafuko-		david.kafuko@nhs.net
Treatment – Rainbow ward- Barts Health – Newham	Newham University Hospital. Glen Road	Consultant Paediatrician -Dr Anjum Bahadur	07823773371	bahadur.anjum@nhs.net
University Hospital	London E13 8RU	Specialist Nurse -Hameeda Rahman	Tel: 02073639071 Mobile: 07734777572	hameeda.rahman@nhs.net
		Assistant Service Manager Paediatrics & Neonatal Services- Abdul Latif Patel	Tel 020 7363 8462 Mob: 07951514554	Abdullatif.Patel1@nhs.net
		Secretary –Bianca Barnett	0207 363 9236	bianca.barnett2@nhs.net



Equality Analysis

Equality analysis is a way of considering the effect on different groups protected from discrimination by the Equality Act, such as people of different ages. There are two reasons for this:

- To consider if there are any unintended consequences for some groups
- To consider if the policy will be fully effective for all target groups

It involves using equality information, and the results of engagement with protected groups and others, to understand the actual effect or the potential effect of your functions, policies or decisions. It can help you to identify practical steps to tackle any negative effects or discrimination, to advance equality and to foster good relations.

Basic details of the analysis			
Fitle of policy etc. being analysed Sickle Cell &Thalassaemia Screening Oper			
	Policy		
Name of person undertaking the	Sekayi Tangayi		
analysis			
Title/Designation	Service Manager/ lead Specialist nurse		
Role in relation to policy being	writer		
analysed			
Directorate	Children &Young People		
Date of analysis 13/02/2020			
Results of the analysis			
☐ No major change required no			
x☐ Adjusted the policy/service			
Continue the policy/service without adjustment			
☐ Stop and remove the policy/service			
Analysis quality checked and approved by:			
Name of quality checker	Paediatric Clinical Governance		
Title/Designation of quality checker	Title/Designation of quality checker Marion Levine- Chair		
Date checked 12/02/2020			

1.	Details of the analysis			
1.1	Title of the policy or service	Transcranial Doppler Ultrasound Scan local Guideline, Stroke Screening for children with sickle cell disease in Newham.		
1.2	Aims of the policy or service	 Identify children with high Doppler's, from the ages of 2 to 16 years old. Monitor them and organise further investigations if needed. If there is evidence of stroke, treatment with regular blood transfusion or hydroxyurea will commence. 		
1.3	Expected outcomes of the policy or service	Stroke screening is intended to identify children with sickle cell disease who are at a high risk of developing an actual stroke. The risk is not the same for all children with sickle cell disease and it is most relevant for children with HbSS and HbS/beta thalassaemia zero.		
1.4	Will the policy or service help to:	Expand on your answer in this column		
	a) Eliminate unlawful discrimination Yes ☐ No ☐v	Yes because service will be offered to all children with above mentioned diagnosis		
	b) Advance equality of opportunity	Yes the service has an open door policy		
	Yes/ No 🗌			
	c) Foster good relations	Yes the services engages the wider public		
4.5	Yes / No .			
1.5	Who will this policy affect? Staff			
	Service Users			
	Carers			
	Members			
	Others/			
2.	Consultation			
2.1	Have you consulted with any of the groups that will be affected by the policy/service etc?	 If 'Yes' state which groups have been consulted and the results of the consultation. If 'No' explain your reasons for not consulting If 'Not yet' state your plans for consulting 		
	Yes □/ No □ Not yet □	The sickle cell & thalassaemia teams		
3.	Evidence			
		Explain your answers in this column		
3.1	In reviewing this policy, service etc. what evidence was looked at? (e.g. staff surveys, service audits, count me in census, workforce reports etc.)	Local audits and national standards		
3.2	Does the evidence show that some	Evidence from the national data suggest that		
	people have not fully benefited from	the policy is of benefits		

	this type of policy or service in the past?	
	Yes ☐ No ☐/	
3.3	Does the evidence show that there is a different take up for this type of policy or service by some people? Yes / No	Yes this test is normally done in hospital.
3.4	Does the evidence show that some	No it does not
3.4	people have been disproportionately affected by the provision that this policy or service hopes to address?	NO IL does not
	Yes 🗌 No 🗌	
3.5	Does this evidence show that some people have been or will be disadvantaged by this policy or service?	No it does not
2.0	Yes No	No
3.6	Were any evidence gaps identified? (e.g. no available data)	No
	Yes 🗌 No 🗌	
3.7	Describe here the action that will be taken to ensure that the policy/service etc. will have a positive impact with reference to 1.4b and 1.4c	We will quality assess via surveys at present doing a DNA audit to assess the need for configuring appointment times.
3.8	Will the policy or service etc. have an impact on Safeguarding Adults?	No
	Yes 🗌 No 🗌	
3.9	Will the policy or service etc. have an impact on Safeguarding Children? Yes □ No □	No
3.10	Will the policy or service etc. have an	No
	impact on Domestic Violence?	
	Yes 🗌 No 🗌	
3.11	Will the policy or service etc. have an impact on Human Rights?	No
	Yes No No	
4.	Monitoring and Review	
4.1	How will the effects of the policy or service be monitored to ensure that it	Monthly KPIs and audit
4.2	addresses the needs of all groups? Who will be responsible for monitoring and reviewing this policy/service etc?	Manager and the team

4.3	When will the policy/service etc. be 12/02/ 2023 reviewed next?			
5.	The findings of the analysis (tick appropriate check box)			
	Findings from the analysis	Explanation	Notes	
/	No major change Tick this box if you do not intend to make any changes to the policy or service etc.	Your analysis demonstrates that the policy or service plans are robust and there is no evidence for discrimination.	If this conclusion is reached, remember to document the reasons for this and the information you used to make this decision. It is also useful to have your analysis quality checked, by a member of the equality team.	
/	The policy/service is to be amended Tick this box if you have identified some changes that need to be made or have been made to the policy or service.	This involves taking steps to remove barriers or to better advance equality. It can mean introducing measures to mitigate the potential effect such as 'Positive Action'.	Remember that it is lawful under the Equality Act to treat people differently in some circumstances.	
	Continue the policy or service Tick this box if you do not intend to make any changes because any potential discrimination can be lawfully justified.	This means adopting your proposals, despite any adverse effect or missed opportunities to advance equality, provided you have satisfied yourself that it does not unlawfully discriminate.	It is objectively justified, it is particularly important that you record what the objective justification is for continuing this policy, and how you reached this decision.	
	Stop and remove the policy or planned service Tick this box if it has been found that the policy/service will be unlawful if it goes ahead.	If a policy or service shows unlawful discrimination it must be removed or changed.	For guidance on what is unlawful discrimination, refer to the Equality and Human Rights Commissions guidance and Codes of Practice on the employment, goods and services and equal pay elements of the Equality Act.	