Whittington Health NHS

Suspected Seizures: management of children and young people (1 month – 17 years)

Subject:	Suspected Seizures: management of children and young people (1 month – 17 years)
Policy Number	N/A
Ratified By:	Clinical Guidelines Committee
Date Ratified:	September 2015
Version:	1.0
Policy Executive Owner:	Clinical Director, Children's services ICSU
Designation of Author:	Consultant Paediatrician (Dr K Robinson)
Name of Assurance Committee:	As above
Date Issued:	September 2015
Review Date:	September 2018 (3 years hence)
Target Audience:	All healthcare professionals treating infants and young people aged 1mth – 17 years at Whittington Health presenting with a fits seizure
Key Words:	Children; seizure; convulsions; epilepsies; fit; childhood

Version Control Sheet

Version	Date	Author	Status	Comment
1.0	Sept 2015	Dr Kerry Robinson Consultant Paediatrician	Live	New guideline approved at Clinical Guidelines Committee (September 2015)

➢ Contents

➢ Summary

This document suggests a guideline for management of children 1 month -17 years presenting with possible seizures to a secondary care clinic or ED setting

NICE have produced guidance that is easily accessible on the internet:

"The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care CG 137" can be found at http://www.nice.org.uk/guidance/cg137

The guideline below is a condensed "need to know" pathway setting out how to manage children and young people with suspected epilepsy presenting to Whittington Health. It is intended that the user will additionally access the website linked above.

➢ Introduction

Epilepsy is a common disease with an incidence in children and adolescents of 1/1000. The epilepsies in childhood have a significant morbidity and mortality. Comprehensive national recommendations for childhood epilepsies were published by the National Institute for Clinical Excellence (NICE) in 2004 (updated in 2012) and the Scottish Intercollegiate Guidelines Network (SIGN) in 2005. Since these publications there has been little evidence of widespread implementation, and ongoing concern that service provision is variable across the UK.

There are more than 40 different types of epilepsy, with 40 different associated seizure types. The nature of epilepsy means that it can be difficult to diagnose accurately. NICE clinical guideline 137 estimates that in 5–30% of people diagnosed with epilepsy the diagnosis is incorrect. The Joint Epilepsy Council (2011) reported that up to 40% of children referred to tertiary epilepsy clinics do not have epilepsy.

➢ Objectives

- To ensure consistent care for all children with suspected seizures
- To ensure we meet criteria set out in NICE guidance and provide high quality care for all children
- To allow audit of practice and service improvement as necessary

➢ Exclusion Criteria

- Neonates (age 0-1 month)
- Children with head trauma, meningeal signs or who are acutely unwell
- Status epilepticus – follow APLS algorithm
- Simple febrile seizures - follow febrile convulsion guidelines

➢ Definitions

A ‘seizure’ or paroxysmal event ‘is a non-specific term used to denote any sudden attack. The term ‘fit’ is used in much the same way. The term ‘convulsion’ is commonly used to denote a sudden attack with prominent motor features. All these terms (often used interchangeably) describe an episode but do not indicate its cause.

An ‘epileptic’ seizure / fit / convulsion is one in which the attack has occurred as a direct consequence of epileptic activity (excessive +/- hypersynchronous discharge of neurones in the brain).

The diagnosis of epilepsy involves recurrent unprovoked epileptic seizures. The epilepsy should be further classified using the international league against epilepsy (ILAE) classification and any other epilepsy syndrome identified.

➢ Development and evidence base

This guideline has been developed using the NICE CG 137 recommendations. It has been additionally developed in conjunction with the North Thames Paediatric epilepsy steering group including key Great Ormond Street Hospital neurologists with the aim that the same guidance will be used across North London paediatric centres.

➢ Assessment of a child/young person with suspected seizures

- It is important to remember that a large number of children presenting with paroxysmal episodes do NOT have epilepsy. Some important differentials can be found in Appendix 1 at the end of this document. If there is any diagnostic doubt, the child / young person should be discussed with the on call / attending consultant or Dr Kerry Robinson (acute paediatrician who can be contacted either via switchboard or her PA, Meredith Dubarry on extension 0207 288 3947) or Dr Katarina Harris (community paediatrician based is Islington who can be contacted via switch or her PA) who run the epilepsy service at Whittington Health.

- The paediatric assessment should include a thorough history, from eye witnesses and symptoms from the child, as well as video recordings where possible. The developmental and family history should be recorded.
- A physical examination; including neurological and skin examination as well as developmental assessment should be performed
- An easy to use proforma for history, examination and subsequent plan can be found in Appendix 2 at the end of this document.
- The aim is to classify the seizure type(s) and identify any possible epilepsy syndrome: as well as to understand any underlying co morbidity

➢ Initial Investigations to consider

- If you are not sure, it is better to discuss with the consultant who will be following up the child or young person in order to avoid unnecessary investigations and anxiety. Sometimes the history alone or a video recording can identify a typical non-epileptic paroxysmal event breath holding or self gratification in a toddler.

- Blood tests including glucose, electrolytes, liver function, calcium and magnesium should be undertaken.

➢ Other Investigations to consider

Video recording

Do encourage the family to capture future episodes where possible, there is a useful leaflet about HOW to video seizures available in Appendix 3 of this guideline.

12-lead ECG

A 12-lead ECG should be performed in children and young people with convulsive seizures. This is to exclude QT abnormalities or arrhythmias. The QTc should be corrected manually and should be less than 0.45seconds (and greater than 0.35seconds)

If in ED or on the wards, this can be done on site

If in out-patients, send the child / young person to ECG with a completed cardiology request form and ask them to return with the ECG for you to assess it contemporaneously. If you just give them the form the ECG invariably gets lost, and also you do not want a delay in diagnosing an arrhythmia.

EEG

EEG requests are processed promptly at Whittington Health. The standard is 6 weeks from request but these are usually completed within 3 weeks regardless of clinical question. A request can be made on ICE (search for neurophysiology). The request goes directly to neurophysiology; there is no need to take a paper copy to them. It is helpful if you include a proper amount of clinical information, particularly when and how frequently the episodes are occurring.

An EEG is NOT needed in a well child after a single paroxysmal episode.

If EEG is necessary, perform it after the second paroxysmal episode, unless evaluation by tertiary neurologist has indicated need for EEG after first seizure

Use EEG

• To support a diagnosis of epilepsy in children in whom the clinical history suggests it

• To help determine the seizure type and epilepsy syndrome which will also aid in prognosis.

Do not use EEG:

• If your clinical suspicion for epilepsy is low (“To exclude a diagnosis of epilepsy”), e. g. in the case of probable syncope (risk of false-positive result), or other types of non epileptic attacks

• In isolation to diagnose epilepsy

Type of EEG

• In the first instance- standard with photic stimulation and hyperventilation but it is worth writing good clincila information on the request form as the neurophysiology team are excellent and will do a sleep EEG if they think it necessary.

• If diagnosis / classification remains unclear – ‘sleep’ EEG (sleep deprivation / melatonin)

• Prolonged / ambulatory recordings can be provided following discussion with the neurophysiology team

• More prolonged telemetry is provided at GOSH

Neuro-imaging

MRI is the imaging investigation of choice in children and young people with epilepsy and is used to identify structural abnormalities that cause certain epilepsies. MRI scans are not available out of hours at the Whittington Hospital.

MRI is particularly important in those:

• Who develop epilepsy before the age of 2 or in adulthood

• Who have any suggestion of a focal onset on history, examination or EEG (unless clear evidence of a benign focal epilepsy)

• In whom seizures continue in spite of first-line medication

• It can also be useful in children with additional impairments (cognitive/ psychiatric / motor)

Do not routinely request MRI if a diagnosis of idiopathic generalised epilepsy has been made

A CT scan is very rarely necessary. The main reason to request would be out of hours in an acute situation to determine if a seizure has been caused by an acute neurological lesion or illness and only if MR is not available. Discuss with a radiologist and the on call consultant first.

It is important that the child stays very still and is prepared for the procedure. Children over the age of 4 years may tolerate MRI with play specialist preparation. Those under a year will require sedation and those aged 1-4 years will usually need a GA which necessitates referral to GOSH as MRI under GA is not available at Whittington Health.

Other tests or assessments

These will be dependent on the age, clinical features, cognitive abilities etc and may include:

• Discussion with a tertiary neurologist if there is diagnostic doubt, especially in children under the age of 2 or as per the agreed North Thames referral pathway (coming soon)

• Psychology / Special Educational Needs Co-ordinator (SENCO) / Educational psychology referral

• Referral to community / neurodevelopmental paediatrics

• Referral to child and adolescent psychiatry

➢ Management

Onwards referral

If it is suspected that child or young person has a diagnosis of epilepsy, then they should be seen in the children and young people's seizure clinic (KR4EC or KH1EC) within two weeks. This is in accordance with NICE guidance. Please email a referral to kerry.robinson@nhs.net this can be a brief email with a scanned photocopy of your clerking attached.

Decision to start regular anticonvulsant medication

Regular anti-convulsant medication should be initiated following discussion with either Dr Robinson/Harris or a paediatric neurologist as appropriate. Usually, medication would be started in the out-patient setting.

The choice of drug and formulation will be agreed between the child/young person / family and the patient's lead paediatrician taking into account:

• Drug recommended by NICE

• Patient / family choice

• Epilepsy type / syndrome

• Developmental stage / ability to take formulation

• Sexual activity in females

Full guidance on which drugs to use, common side effects and other tips are available on the NICE patient pathway.

Written and verbal information common and rare side effects should be given

Routine blood drug level monitoring is no longer recommended in children

A good website to print off drug information for families is *www.medicinesforchildren.co.uk*

Buccal Midazolam and Emergency Seizure plans

A new diagnosis of epilepsy can be very stressful for patients, parents and schools who want clear guidance on what to do should the child have a further seizure. An emergency seizure plan will be developed following the first attendance in the out-patient department or ward as appropriate.

Children and young people who have experienced a convulsive seizure lasting greater than 5 minutes or serial convulsive seizures should be offered Buccal Midazolam (Buccolam). The preparation 'Buccolam' comes in pre-filled syringes in packs of 4. Remember that this is a controlled drug so you need to prescribe accordingly and arrange training (see below):

• 3mths to <1 year 2.5mg

• 1yr to <5yrs 5mg

• 5 yrs to <10 yrs 7.5mg

• 10yr+ 10mg

A Buccolam information leaflets is available on the intranet.

Parents are often reassured to receive basic life support training. This should be provided if Buccal Midazolam is prescribed. Training can be provided by nurses on Roses Day Care on ext 3769 (children's day care unit)

Depending on where the child lives, community or school nurses can often provide additional support and education to family members and teachers.

Local paediatric epilepsy nurses.

Safety and other advice

Please use the leaflet available on the intranet – under Paediatrics labelled' First seizure in children and young people, Information for parents and carers'

This should be provided according to age and medication and should include where relevant:

• Bathing / water safety / swimming

• Cycling

• Climbing

• Contraception / sexual health

• Driving

Other useful information for families:

Parents / children's / adolescent handbooks are available from Kerry Robinson and are offered in the case of a new diagnosis of epilepsy.

Useful websites for professionals and families to access include

• Epilepsy Action: http://www.epilepsy.org.uk/

• Young Epilepsy: http://www.youngepilepsy.org.uk/

• The epilepsy society: http://www.epilepsysociety.org.uk/

• The international league against epilepsy: http://www.ilae.org/

Review, Monitoring & Compliance

The management of children's epilepsy at Whittington Health will be regularly audited through the National Epilepsy 12 audit that takes place every two years. This essentially monitors compliance with NICE and hence these guidelines.

The paediatric governance and Trust audit committees will monitor the guidelines biannually

The monitoring will be reported and actioned at Trust and paediatric and adolescent audit and governance committees

➢ References (evidence upon which the guideline is based)

Nice Guideline, CG 137, Published date Jan 2012 (accessed Sept 2015)

http://www.nice.org.uk/Guidance/cg137

➢ Appendix 1

Differential Diagnoses of fits faints and funny turns (ie things that are NOT epilepsy)
These can be thought about in broad groups depending on what the main presenting feature.

Differential diagnosis of blank episodes:

Day dreaming
Self-gratification
Hyperventilation
Psychogenic seizures

Differential diagnosis of convulsions:

Simple faint (vasovagal attack)
Reflex anoxic seizure
Breath holding episodes
Cardiac syncope
Psychogenic

Differential diagnosis of drop attacks:

Cataplexy
Paroxysmal vertigo
Paroxysmal choreoathetosis
Posterior fossa/3rd ventricle problems
Psychogenic

Differential diagnosis of stiffening attacks:

Dystonia
Herniation
Hyperekplexia (excessive response to startle followed by stiffening)
Psychogenic

Differential diagnosis of funny movements:

Tics and mannerisms

Paroxysmal dyskinesias

Paroxysmal torticollis

Non epileptic myoclonus

Shuddering attacks

Differential diagnosis of attacks from sleep:

Nightmares

Night terrors

Benign Sleep Myoclonus

Sleep starts

➢ Appendix 2

See next page – please print out and use as notes if you would like

Medical Assessment of **First Fit / Faint / Funny Turn**

Paediatric Department, Magdala Avenue, London, N19 - 5NF tel. 020 7288 3947

Name

dob

GP Dr

GP Address

WH #

tel.

Date

Consultant ☐ KR ☐ KH Source GP ☐ ED ☐ 10-12 ☐ Ward ☐ Other ☐

Reason for Referral

History of First Episode:

Video recording obtained?

Event

Preceding

Where was child?

Onset

Progression

Ending

Post ictal?

Subsequent Episodes

Medication

Current Medication

(name, dose per kg, date started)

Previous Medication

(name, dose per kg, date started, date stopped, reason for stopping)

Allergies?

Investigations & dates performed

ECG

EEG

MRI

Bloods

Urine

LP

Other

Previous Medical History

Birth History

Pregnancy

Gestational age

Birth history/weight

Peri-natal

Past Medical History + Imms

Development

Age of:

- Smiling
- Sitting unsupported
- Walking independently
- First word
- Talking in sentences

Behavioural/emotional difficulties

Family History & Social History

Please draw a family tree: Annotate with names, ages, health problems and parental occupations

Consanguinity

Learning difficulties/epilepsy

Languages at home

Childcare

Housing

School

Learning needs/statement

School progress/attendance

Child Protection Plan

Examination & Observations

Weight kg Height / Length cm OFC cm

Centiles

General

Dysmorphic features

Neurocutaneous stigmata

Speech/behaviour

Cranial Nerves

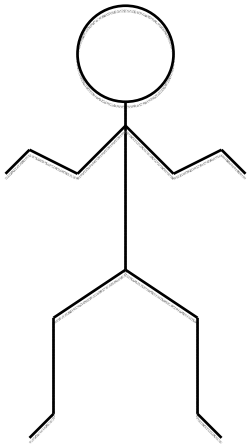
I VIII

II	IX
III, IV, VI	X
V	XI
VII	XII

Fundoscopy

Reflexes:

	Left	Right
Upper Limb	Tone Power Co-ordination	Tone Power Co-ordination
Lower Limb	Tone Power Co-ordination	Tone Power Co-ordination



Sensation

Dysdiadochokinesis

Finger isolation

Past-pointing

Heel-toe walking

CVS

Respiratory

Abdominal

Investigations Requested (following this visit)

Home Video

EEG

MRI

ECG

Bloods

Urine

LP

Other

Medications Adjusted (following this visit)

(Name, dose, side effects discussed?)

Buccal midazolam prescribed?

Treatment options discussed?

Discussions had with patient and family:

Safety/ lifestyle advice given: bath/showers, helmets, road crossing, swimming

Pregnancy/ contraception

SUDEP (sudden unexplained death in epilepsy

Individual care plan

Written information given

Follow up arrangements

Case discussed with

Completed By:

Signed ***PRINT*** ***Doctor***

PRINT ***Nurse***

- **Appendix 3**

A guide to filming seizures

There are times when it can be difficult to know what is causing the ‘epispodes’ that someone is having. One way that can help is to film the episodes. Film clips can be captures on phones, ipads, digital or video cameras. To make sure the film is as helpful as possible we have put together the following suggestions:

Preparing the device:

Keep the device easily available so you can get it quickly.

Make sure the battery is fully charges

Filming each episode:

If your child needs first aid or help then this always takes priority

It is useful to be able to see the whole child (eg. Not just the face, pull back the duvet etc)

Make sure there is plenty of light

Ideally we would like the whole episode, from ‘before the start’ to ‘after the finish’. Often this is not possible so any part is useful.

For some types of episodes, try to talk to them or clap your hands to see if they will respond to you.

After the episode you can record the date, time and the name you give to the type of episode verbally on the clip.

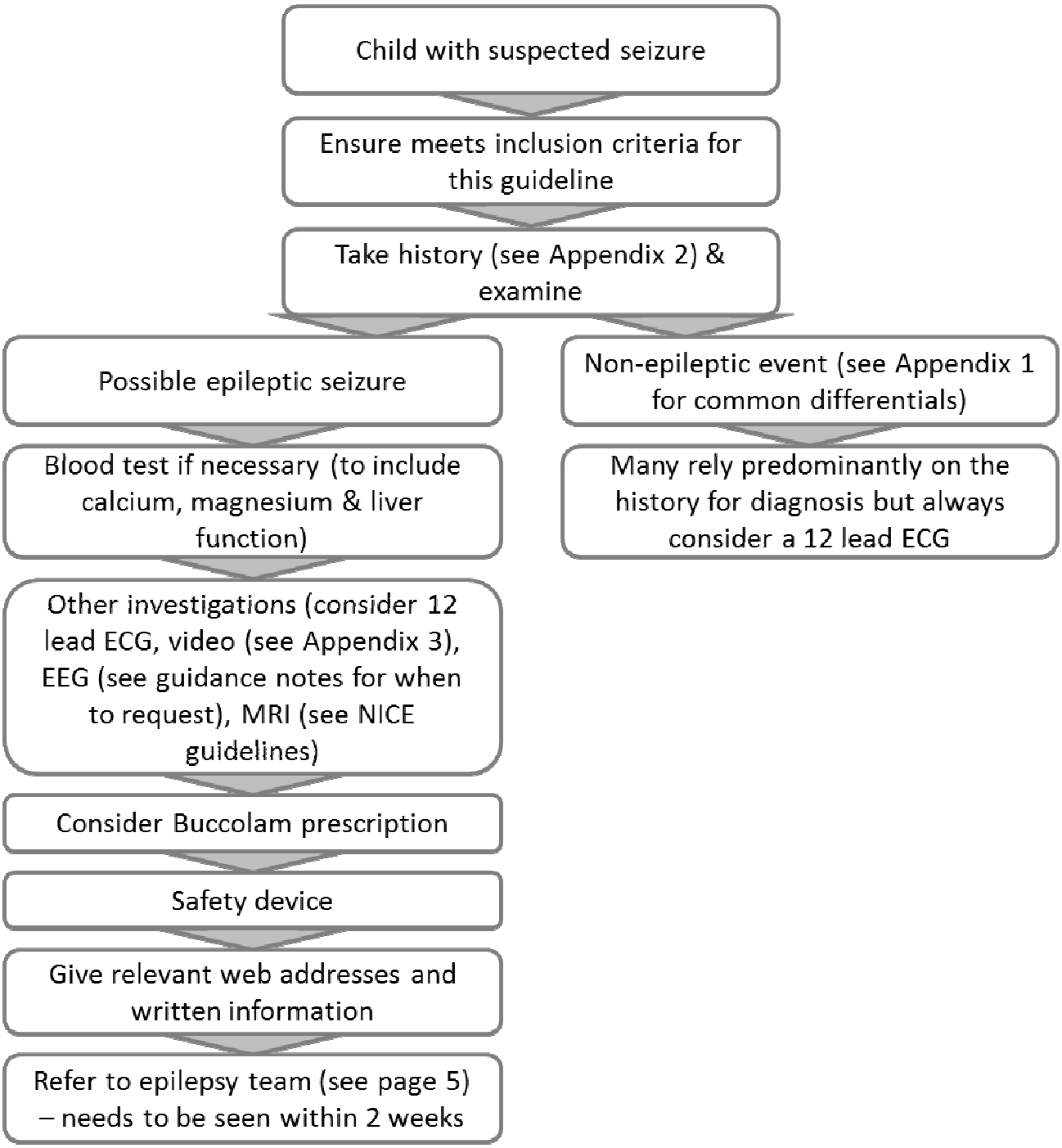
After filming:

Keep the clip

Record the date, times and a description of the episode. It is helpful if you write this down – it helps your doctor understand how you describe the events.

Bring it to your next clinic appointment

➢ Appendix 4


Child with suspected seizure
Ensure meets inclusion criteria for this guideline
Take history (see Appendix 2) & examine
Possible epileptic seizure
Blood test if necessary (to include calcium, magnesium & liver function)
Other investigations (consider 12 lead ECG, video (see Appendix 3), EEG (see guidance notes for when to request), MRI (see NICE guidelines)
Consider Buccolam prescription
Safety device
Give relevant web addresses and written information
Refer to epilepsy team (see page 5) – needs to be seen within 2 weeks
Non-epileptic event (see Appendix 1 for common differentials)
Many rely predominantly on the history for diagnosis but always consider a 12 lead ECG

Tool to Develop Monitoring Arrangements for Policies and guidelines

What key element(s) need(s) monitoring as per local approved policy or guidance?	Who will lead on this aspect of monitoring? Name the lead and what is the role of the multidisciplinary team or others if any.	What tool will be used to monitor/check/observe/ Assess/inspect/ authenticate that everything is working according to this key element from the approved policy?	How often is the need to monitor each element? How often is the need complete a report ? How often is the need to share the report?	What committee will the completed report go to?
Element to be monitored	**Lead**	**Tool**	**Frequency**	**Reporting arrangements**
Adherence to guideline content.	**Dr K Robinson**	**Clinical Audit**	**Initial audit scheduled for 2 years post introduction**	**Relevant paediatric group**

To be completed and attached to any procedural document when submitted to the appropriate committee for consideration and approval

		Yes/No	Comments
1.	**Does the procedural document affect one group less or more favourably than another on the basis of:**		
	• Race	No	
	• Ethnic origins (including gypsies and travellers)	No	
	• Nationality	No	
	• Gender	No	
	• Culture	No	
	• Religion or belief	No	
	• Sexual orientation including lesbian, gay and bisexual people	No	
	• Age	No	
	• Disability - learning disabilities, physical disability, sensory impairment and mental health problems	No	
2.	**Is there any evidence that some groups are affected differently?**	No	
3.	**If you have identified potential discrimination, are any exceptions valid, legal and/or justifiable?**	No	
4.	**Is the impact of the procedural document likely to be negative?**	No	
5.	**If so can the impact be avoided?**	N/A	
6.	**What alternatives are there to achieving the procedural document without the impact?**	N/A	
7.	**Can we reduce the impact by taking different action?**	N/A	

If you have identified a potential discriminatory impact of this procedural document, please refer it to the Director of Human Resources, together with any suggestions as to the action required to avoid/reduce this impact.

For advice in respect of answering the above questions, please contact the Director of Human Resources.

Checklist for the Review and Approval of Procedural Document

To be completed and attached to any procedural document when submitted to the relevant committee for consideration and approval.

	Title of document being reviewed:	Yes/No	Comments
1.	**Title**		
	Is the title clear and unambiguous?	Yes	
	Is it clear whether the document is a guideline, policy, protocol or standard?	Yes	
2.	**Rationale**		
	Are reasons for development of the document stated?	Yes	
3.	**Development Process**		
	Is it clear that the relevant people/groups have been involved in the development of the document?	Yes	
	Are people involved in the development?	Yes	
	Is there evidence of consultation with stakeholders and users?	Yes	
4.	**Content**		
	Is the objective of the document clear?	Yes	
	Is the target population clear and unambiguous?	Yes	
	Are the intended outcomes described?	Yes	
5.	**Evidence Base**		
	Are key references cited in full?	N/A	
	Are supporting documents referenced?	N/A	
6.	**Approval**		

	Title of document being reviewed:	Yes/No	Comments
	Does the document identify which committee/ group will approve it?	Yes	
7.	**Dissemination and Implementation**		
	Is there an outline/plan to identify how this will be done?	Yes	
8.	**Document Control**		
	Does the document identify where it will be held?	Yes	
9.	**Process to Monitor Compliance and Effectiveness**		
	Are there measurable standards or KPIs to support the monitoring of compliance with and effectiveness of the document?	Yes	
	Is there a plan to review or audit compliance with the document?	Yes	
10.	**Review Date**		
	Is the review date identified?	Yes	
	Is the frequency of review identified? If so is it acceptable?	Yes	
11.	**Overall Responsibility for the Document**		
	Is it clear who will be responsible for co-ordinating the dissemination, implementation and review of the document?	Yes	

Executive Sponsor Approval			
If you approve the document, please sign and date it and forward to the author. Procedural documents will not be forwarded for ratification without Executive Sponsor Approval			
Name		Date	
Signature			
Relevant Committee Approval			

The Director of Nursing and Patient Experience's signature below confirms that this procedural document was ratified by the appropriate Governance Committee.			
Name		Date	
Signature			
Responsible Committee Approval – only applies to reviewed procedural documents with minor changes			
The Committee Chair's signature below confirms that this procedural document was ratified by the responsible Committee			
Name		Date	
Name of Committee		Name & role of Committee Chair	
Signature			