

Joint Trust Guideline for the Management of Children and Young People coming to hospital for Inpatient and Outpatient Treatment and/or Investigation who have Social Communication Disorders (SCD) (Including Autistic Spectrum Disorders (ASD))

A Clinical Guideline

For Use in:	The Children/young people's department and all clinical areas providing treatment/investigation for children/young people and young people
By:	All staff providing care in the above areas
For:	All children/young people and young people under the care of Norfolk and Norwich University NHS Trust and the James Paget University Hospital (JPUH)
Key words:	Social Communication Disorder (SCD), Autistic spectrum disorder (ASD), autism
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Assessed and approved by the:	Clinical Guidelines and Assessment Panel (CGAP) Chairs Action
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To be reviewed before: This document remains current after this date but will be under review	14/08/2022
To be reviewed by:	Emma Chapman, Dr B Alden
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Compliance links: e.g. NICE	None

This guideline has been approved by the Trust's Clinical Guidelines Assessment Panel as an aid to the diagnosis and management of relevant patients and clinical circumstances. Not every patient or situation fits neatly into a standard guideline scenario and the guideline must be interpreted and applied in practice in the light of prevailing clinical circumstances, the diagnostic and treatment options available and the professional judgement, knowledge and expertise of relevant clinicians. It is advised that the rationale for any departure from relevant guidance should be documented in the patient's case notes.

The Trust's guidelines are made publicly available as part of the collective endeavour to continuously improve the quality of healthcare through sharing medical experience and knowledge. The Trust accepts no responsibility for any

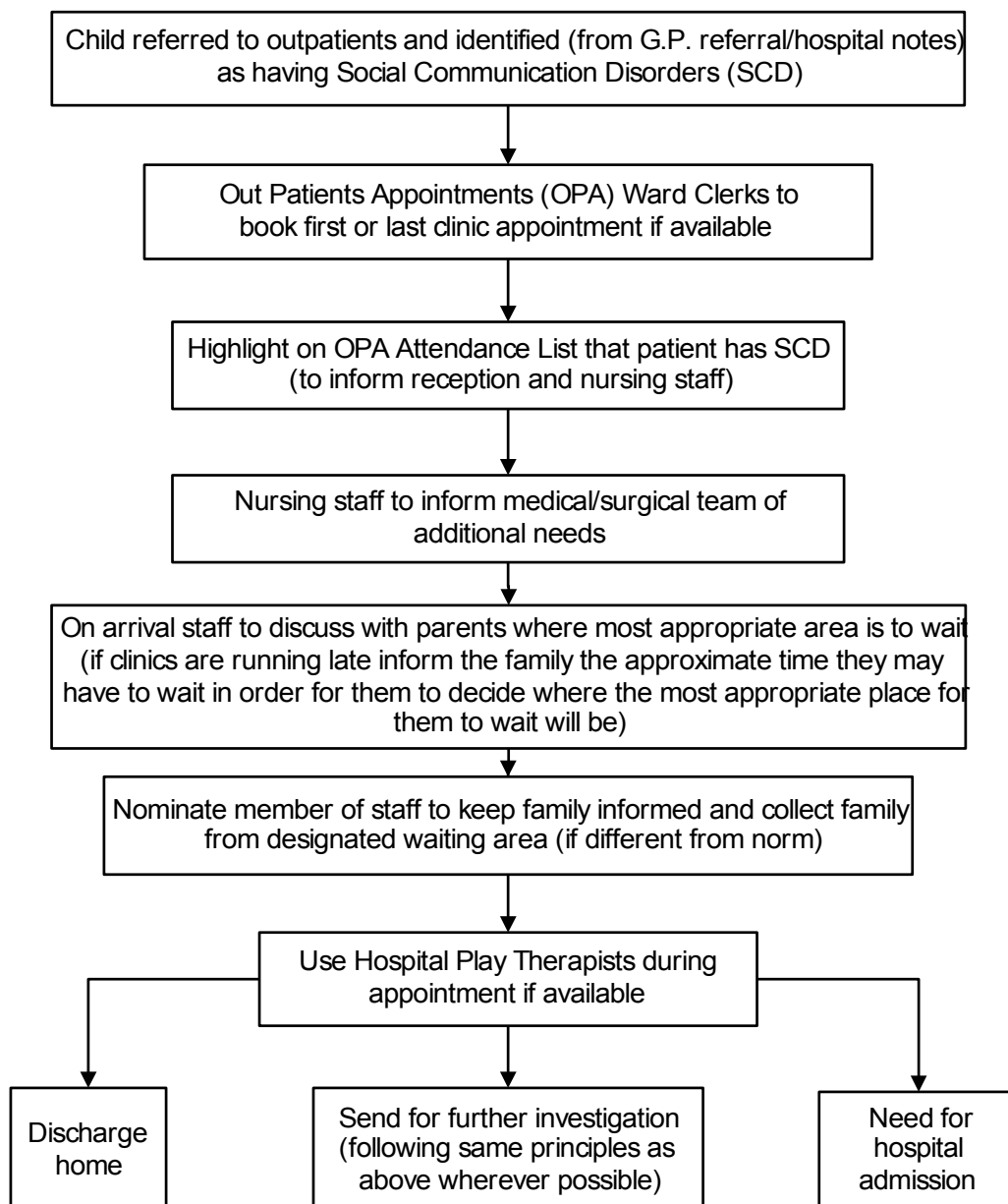
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[misunderstanding or misapplication of this document.](#)

Quick Reference Guideline/s

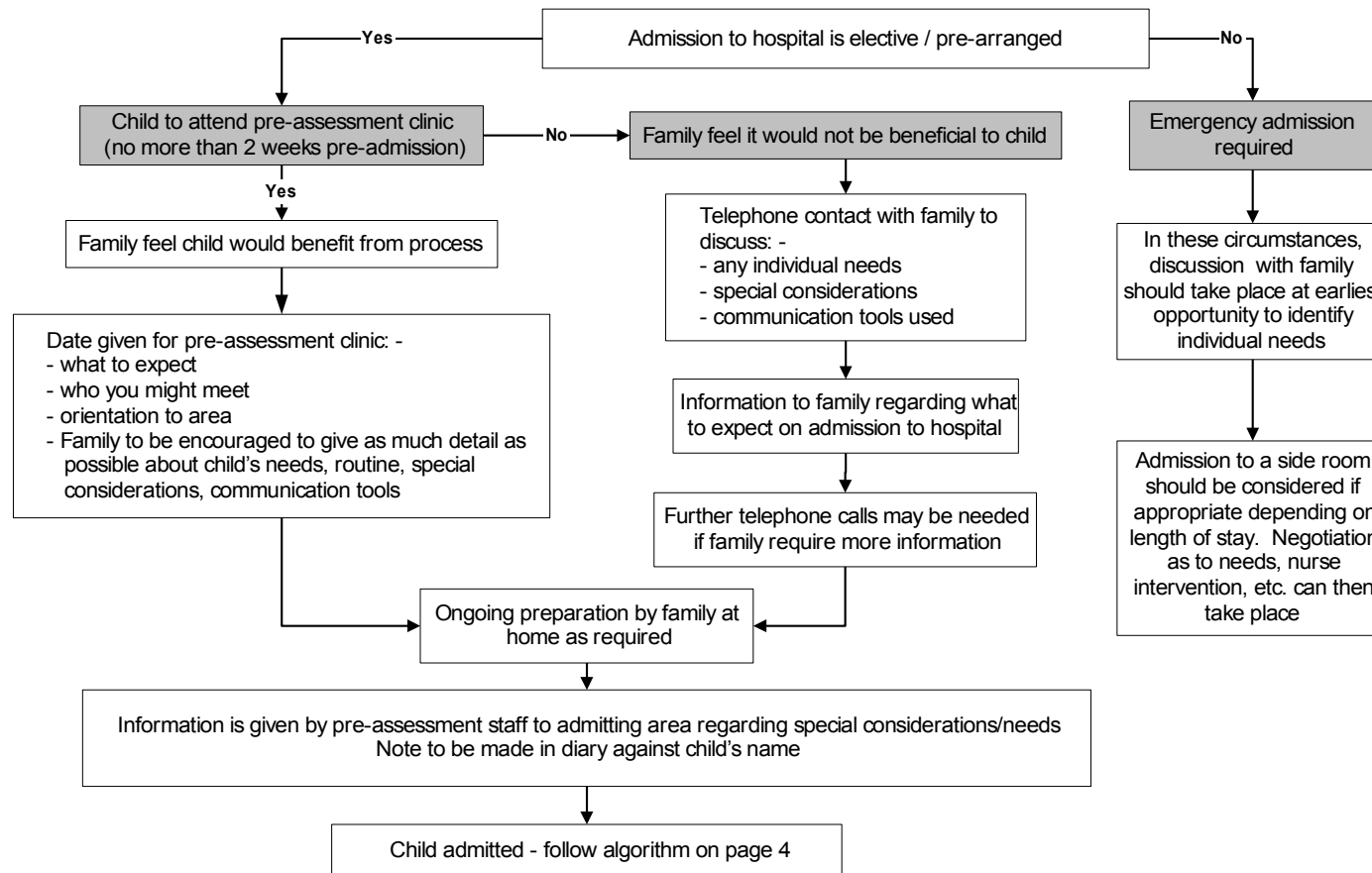
**CHILDREN/YOUNG PEOPLE COMING TO HOSPITAL FOR
OUTPATIENT APPOINTMENT / INVESTIGATION**

**CHILDREN WITH SCD HAVE EXCELLENT MEMORIES
A POSITIVE EXPERIENCE WILL MAKE SUBSEQUENT
VISITS EASIER TO DEAL WITH**



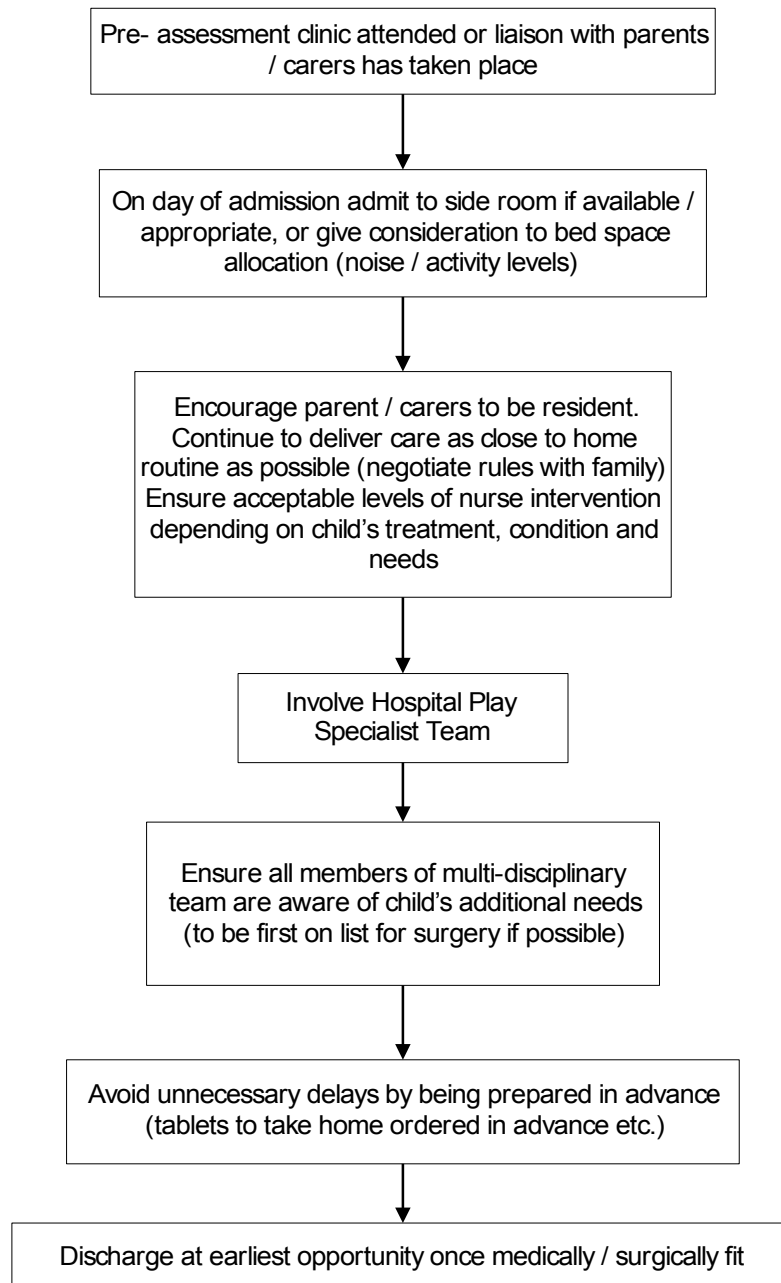
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Children with Social Communication Disorders attending Hospital for Inpatient Care



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CONSIDER THE INDIVIDUAL - WHAT SUITS ONE CHILD MAY NOT SUIT ANOTHER

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Objective

To inform all staff employed by the Trust who comes into contact with children/young people/young people with social communication disorders (including autism) that these children/young people/young people may have additional communication requirements and needs to ensure their hospital visit is made as stress free for the child/young person and carer as possible. To provide information for staff employed by the Trust as to some of the actions which could be taken to reduce any potential problems encountered by these children/young people/young people and their families when coming to hospital? To ensure each child/young person is treated as an individual and is cared for with sensitivity, whilst working in partnership with the family.

Rationale

While many children/young people/young people with Social Communication Disorders (SCD) have no other medical problems, SCD, in particular Autistic Spectrum Disorder (ASD), are well recognised to be associated with increased frequency of a number of additional medical and psychiatric conditions. These include Gastrointestinal disorders (constipation, abdominal pain, gastroesophageal reflux), epilepsy, feeding and sleep disorders, anxiety and OCD. SCD can also be a feature in children/young people/young people with complex medical and genetic disorders. With regard to this background, it can be expected that a significant number of children/young people/young people attending in- and outpatient appointments will have a comorbid diagnosis of SCD.

NICE guidance and recommendations from the National Autistic Society advise that healthcare professionals and hospitals should take into account the physical environment in which children/young people and young people with autism are cared for and seek to minimise any negative impact.

Problems in communication and extreme sensitivity could make a hospital visit a challenge for the child/young person, family and health professional. The implementation of some or all of the suggested practical measures may assist in making the experience a positive one reducing the stress felt by the child/young person and family.

Broad recommendations

Refer to algorithms on page 2, 3 and 4.

For further information please refer to the Trusts Learning Disabilities Pack and the clinical area Link Nurse for Learning Disabilities.

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Introduction

Children/young people who have SCD may have significant difficulty understanding the need for and process of a hospital visit, sometimes resulting in inappropriate behaviour. Unusual and challenging behaviours are often present and may be displayed as:

- extreme reactions to minor changes,
- unusual sensitivities to particular sounds, sights or textures,
- compulsive routines
- repetitive motor behaviours.

The following are some core areas which may cause children/young people distress when coming into hospital.

1. **Social Communication:**

Many children/young people have considerable difficulty in communicating with others. This applies not only to those children/young people who have limited verbal ability but also those children/young people and young people who can use speech but may fail to understand many of the subtleties of social communication (see later).

2. **Social Interaction:**

Children/young people and young people who have social communication disorders may find it difficult to respond appropriately and as a consequence appear either aloof or over friendly. They may find it difficult to relate to children/young people of a similar age.

3. **Change of routine or environment:**

Many children/young people/young people find the challenge of entering a new environment overwhelming and very stressful.

4. **Unusual sensitivity to sensory stimuli:**

It is not unusual for young people with social communication disorders to find sounds, lights, smells and textures overwhelming. They may express their distress by demonstrating challenging behaviour.

Appointments

- Waiting in hospital outpatient areas will increase the stress levels of an already anxious child/young person.
- Where possible identify children/young people with SCD/ASD during the clinic referral triage process and consider liaising with the family prior to allocating an appointment if medical records suggest attending clinic could be particularly challenging or stressful.

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- Try to give patients with ASD/SCD the first or last appointment of the day and/or consider allocating double clinic slots to ensure enough time is available to manage the issue.
- Ensure the consultant/healthcare professional in charge of the clinic is aware of the child's/young person's additional needs, and that they are waiting to be seen, particularly if a clinic is overrunning, in case alternative provision is possible.
- If possible find a side room or quiet area where they can wait. However some children/young people may find this claustrophobic and each child's/young person's needs should be considered individually. The parent/carer would be able to help make this decision.
- The family may prefer to wait outside or in their car and a member of staff should be identified to collect them when appropriate. If the appointment is likely to be delayed the family may wish to leave and return at a later agreed time.

Communication

- Children/young people with SCD have the same rights as all other children/young people to have their feelings and wishes taken into account and wherever possible to be involved in shared decision making. Achieving this will require good communication skills with both the child/young person and carers.
- Where possible encourage the child's/young person's carers to try to prepare the child/young person for likely events and procedures in advance i.e. through pre-planned introductory visits to hospital and/or use of social stories. Additional resources are available on the National Autistic Society website www.autism.org.uk/about/health/doctor.aspx
- Consider gathering additional information about the child/young person using documents such as a health passport to ensure all needs are understood and met. Patients may wish to use the hospital passport created by the national Autistic Society (free to download) www.autism.org.uk/about/health/hospital-passport.aspx
- Always explain what you are going to do before starting any procedure or examination.
- Use clear simple language with short sentences and avoid irony, metaphors and words with double meanings. Avoid using body language, gestures or facial expressions without verbal instructions. These may not be understood.
- Give direct requests e.g. "Please stand up" rather than "can you stand up" which might result with a response of "yes"
- Ask for the information you need. A child/young person with ASD may not volunteer vital information without being asked.
- If possible show a picture to aid explanation. Visual prompts are helpful for all children/young people who have SCDs even those who have excellent verbal communication and are especially helpful when they are stressed or anxious.

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- Allow extra time for the child/young person to process what you have said
- Children/young people with ASD tend to take everything literally so by saying “it will only hurt for a minute” they will expect it to only last one minute.
- Check (depending on their age) that they have understood what you have said.
- Don't be surprised if the patient doesn't make eye contact. Lack of eye contact does not necessarily mean they are not listening.
- Don't assume that a non-verbal patient cannot understand what you have said.
- People with ASD find it difficult to understand another person's perspective. They may not understand what you intend to do but may expect you to know what they are thinking.
- Children/young people with ASD may not understand personal space. They may invade your personal space or need more personal space than the average person.

Physical Examination

Although parents / carers will have given consent to physical examination it is essential to explain simply to the child/young person what you are planning to do and why.

Despite this warning the experience may still be stressful.

- Enlist the parent/carers help whenever possible, especially if the patient is non verbal or uses an alternative communication method.

Sensory Stimulation

Lights

- Some people with ASD are extremely sensitive to light and can discern the flashing of fluorescent lights.
- Pen lights can trigger seizures in susceptible individuals. Seizures can occur in 20-30% of people with ASD.

Sensory Overload

- It is easy for someone with ASD to be overcome by sensory overload. *Emergency lights and machines, general hustle and bustle and unfamiliar sounds can be agonising to the person with ASD.*
- Whereas some might withdraw (e.g. put their fingers in their ears, close their eyes) others may flap hands, flick fingers or rock backwards and forwards. *This kind of behaviour is calming to the individual so do not try to stop it unless absolutely essential.*

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Pain

- People with ASD can have difficulties responding appropriately to pain. They may not exhibit pain.
- They may show an unusual response to pain that could include laughter, humming, singing or removal of clothing.
- Agitation and behaviour may be the only clues that the child/young person is in pain.

Injections and blood tests

- Try to minimise the length of time the child/young person is waiting before any invasive procedure/treatment. The hospital environment is likely to be stressful and the more stressed the child/young person is, the more difficult it will be to safely carry out the procedure. Consider environmental adjustments as listed above (under Appointments).
- Try and divert the child's/young person's attention elsewhere (play therapists should be used if available).
- Using pictures is a good idea.
- Using a doll to demonstrate may also be helpful.
- Children/young people with ASD may be under or over sensitive to the pain therefore some may be very distressed and others show no reaction at all.
- Use Emla or Ametop cream as per Patient Group Directions (PGDs) 87.1 and 90.1. Parents may prefer not to wait for the cream to work if waiting is going to distress the child/young person. Ethyl Chloride spray may be a suitable alternative or supplying the cream before the hospital visit with instructions for parents to apply before coming to hospital.

Accident and Emergency

Accident and Emergency can be totally overwhelming for a child/young person with ASD. It is not only a strange place and seemingly chaotic but the sensory experience of bright lights, beeping monitors and other equipment can completely overload their system causing extremes in behaviour. Possible behavioural outbursts or withdrawal may be seen.

- The triage nurse should establish that the patient has ASD and discuss with carers the most appropriate area for the patient to be treated in
- Try to limit the number of staff caring for the patient- allocate a key person if possible.
- Dependent on departmental pressure the staff should try and minimise the length of time the patient will have to wait to be seen.
- Keep the family informed as to why they are waiting
- Allow the parent or carer to take control as they will know the best way to calm the patient down providing that the parent is willing to do this.

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- Allow the parent/carer to stay with the child/young person whilst treatment is being given whenever possible (if the parent is comfortable with this arrangement).
- If the child/young person requires admission to the ward ensure this happens promptly and that the flow through the department is constant.

Admission to hospital

Admit the child to a side room if available or clinically required. If unavailable look at admitting the child/young person to the quietest area of the ward e.g. away from crying babies, noisy machines, televisions etc.

If the admission is elective encourage the child/young person and family to attend the pre assessment process to familiarise the child/young person to new surroundings, look at specific requirements of the individual child/young person (with specific reference to the child's/young person's daily routine) and begin the preparation process for surgery. (play therapists will be a pivotal role in preparing the child/young person and family). *Some families may feel that attending the pre assessment clinic may be more stressful for the child/young person than not attending. A telephone conversation may be more appropriate in these circumstances particularly with regard to finding out the individual child's/young person's specific requirements.*

Encourage the family to bring in any communication tools they use at home (e.g. picture boards).

Encourage the parent or carer to stay in hospital with the child/young person if possible.

Plan in advance as best as possible to pre-empt any likely delays e.g. waiting for discharge medications.

Ensure all Multi-disciplinary Team members are aware of the admission of the child/young person so that the additional needs of children/young people with SCD can be considered and unnecessary delays avoided.

In conjunction with parent/carer consider use of a reward system for the child/young person by reinforcing positive behaviour.

Clinical Audit Standards derived from guideline

To ensure that this policy is compliant with the above standards, the following monitoring processes will be undertaken:

- A retrospective review of complaints, PALS reports and incidents will be conducted and any issues addressed.
- A staff questionnaire will be undertaken to ascertain staff understanding of the guideline and to address any training issues that arise as a consequence.

The audit results will be sent to Senior Nurse, Paediatric Inpatients, and the Clinical Director for Paediatrics who will review the results and make recommendations for further action.

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Summary of development and consultation process undertaken before registration and dissemination

The authors listed above on behalf of a guideline development group, which has agreed the final content, drafted the guideline. During its development it has been circulated for comment to: Paediatricians and staff in clinical areas where children/young people are seen with in the Trust.

The final version incorporates their comments and has been endorsed by the Clinical Guidelines Assessment Panel (CGAP).

Distribution list/ dissemination method

Trust Intranet via 'Trust Docs'

References/ source documents

NICE Guidance: Autism spectrum disorder in under 19s: support and management. Clinical guideline [CG170] Published date: August 2013. Reviewed 2016

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