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Appendix 1: Equality Impact Assessment

1.0 Purpose

- 1.1 The purpose of this guideline is to provide staff with an evidence based up to date management plan for children presenting with nephrotic syndrome, which ensures that every case of nephrotic syndrome follows the same clinical pathway.
- 1.2 Consistent management for nephrotic syndrome facilitates the counselling of parents and reduces their anxiety levels after the initial diagnosis.

2.0 Equality Impact Assessment

- 2.1 Mid Essex Hospital Services NHS Trust is committed to the provision of a service that is fair, accessible and meets the needs of all individuals.
(Refer to Appendix 1)

3.0 Introduction

- 3.1 Idiopathic nephrotic syndrome (NS) is the commonest chronic glomerular disorder of childhood with an incidence of 2-4 cases per 100,000 children in the UK with a greater prevalence among the Asian populations.
- 3.2 NS encompasses a number of diseases. On average 78% of cases are due to minimal change disease (MCD), 8% FSGS, 6% membranoproliferative glomerulonephritis and 8% others.
- 3.3 **Classification** - one can also classify NS according to sensitivity to steroids. Typically, 80% patients respond to oral corticosteroid therapy (**Steroid sensitive**). 75-85% of these children will experience a relapse.
 - 3.3.1 **Frequent relapsing** defined as 2 relapses within 6 months of initial response *or* 4 or more relapses within *any* 12-month period.
 - 3.3.2 Patients who relapse as the steroid dose is being tapered or within 2 weeks of discontinuation of steroid therapy are termed **Steroid dependant**.
 - 3.3.3 5% fail to go into remission despite 8 weeks of high dose steroid therapy who are termed **Steroid resistant**.
- 3.4 **Treatment Goals**

The primary treatment objective is to achieve remission, alleviate symptoms and prevent/treat acute risks such as infection, thrombosis, hypovolaemia etc.

The long- term treatment objective is to prevent complications like bone disease, hypertension, Cushing syndrome, obesity, growth retardation, striae, cataracts and a variety of psychological, social and behavioural disturbances.

4.0 Definitions

4.1 Nephrotic Syndrome;

- Proteinuria more than or equal to 3+ on dipstick (UA/UC >200mg/mmol);
- Oedema;
- Plasma Albumin less than 25g/l;
- \pm Hyperlipidaemia.

4.2 Remission

- Proteinuria trace/-ve for 3 consecutive days irrespective of loss of oedema.

4.3 Relapse

- 3+ protein for 3 consecutive days or 5 days of 2+ proteinuria on early morning urine analysis / proteinuria with oedema.

5.0 Management of Initial Episode

5.1 Clinical history

To include history of:

- Atopy;
- Immunisations;
- Natural childhood infections (particularly Varicella Zoster);
- Family history (particularly renal disease and thrombophilia).

All children should be admitted until deemed to be safe to be discharged after discussion with the consultant on call.

5.2 Clinical examination

To include:

- Height, weight, estimated body surface area (NB – an estimate of dry weight will give a more accurate surface area estimate);
- Blood pressure;
- Assessment of oedema (lower limb, sacral, ascites, scrotal, pleural effusions?);
- Cardiovascular status and perfusion (volume status):
 - Indicators of fluid overload: tachycardia, hypertension, respiratory distress, warm peripheries, hepatomegaly, raised JVP;
 - Indicators of hypovolaemia: tachycardia, hypertension, cool peripheries, delayed capillary refill time.

5.3 Baseline Investigations

5.3.1 Children presenting with typical nephrotic syndrome are frequently over-investigated. Providing the history is consistent with typical nephrotic syndrome, the following investigations are all that is required as a baseline assessment for diagnosis and surveillance for complications.

Urine tests	Blood tests
Urinalysis for protein and blood	Electrolytes, urea and creatinine,
Protein: creatinine ratio (early morning sample if possible)	Bone profile (including albumin)
	Full blood count
	Varicella zoster immunity status

5.3.2 Raised urea or haemoglobin may be markers of hypovolaemia. Elevated creatinine can indicate atypical nephrotic syndrome and is an indication for discussion with a paediatric nephrologist.

5.3.3 Plasma lipids, complements and hepatitis serology are not relevant investigations for a first episode of typical nephrotic syndrome.

5.3.4 Plan tests: single venepuncture is ideal in children who may be difficult to bleed because of oedema. Femoral stabs should never be performed as thrombosis is a described complication.

5.3.5 On-going blood tests are only necessary for children receiving albumin infusions, diuretics or to follow-up initial abnormal results.

5.4 Typical versus atypical nephrotic syndrome

5.4.1 Children with an atypical initial presentation of nephrotic syndrome are less likely to have minimal change disease and may not be responsive to steroids. They may require biopsy before initiating treatment and should always be discussed with a paediatric nephrologist.

Criteria	Typical nephrotic syndrome	Atypical nephrotic syndrome
Age	1-11 years	<1 or >11 years
Renal function	Normal creatinine	Elevated creatinine
Haematuria	Microscopic may occur	Macroscopic
Hypertension	Usually normotensive	Elevated
Family history of nephrotic syndrome	Usually absent	May be present

5.5 Indications for discussion with a paediatric nephrologist at presentation

5.5.1 The nephrotic state can be complicated by hypovolaemia, thrombosis and infection. If there are any of the following features during the initial presentation, the child should be discussed with a consultant paediatric nephrologist:

- Any atypical features as above;
- Suspicion of hypovolaemia from clinical assessment or elevated haemoglobin/urea;
- Before giving intravenous albumin.

5.6 Investigations for presenting with atypical features

5.6.1 Patients presenting with atypical features may require additional investigations and/ or immediate referral or discussion with tertiary nephrology services

- If there is positive family history, genetic analysis may be indicated;
- Hypertension;
- Macroscopic haematuria: **Please do** C3, C4, Immunoglobulins, antinuclear; antibodies (ANA), anti-streptolysin O Titre (ASOT, Anti-Neutrophil Cytoplasmic Antibodies (ANCA);
- Hypocomplementaemia: C3, C4 and
- Renal impairment- in the absence of dehydration or nephrotoxic- refer to GOSH.

6.0 Initial Management Protocol

(Refer to Table 1)

6.1 Prednisolone 60 mg/m²/day, equivalent to 2mg/kg/day, for 4 weeks. Maximum daily dose of 60mg given as a single **morning** dose.

6.2 In the presence of hypertension start twice daily dosing i.e. 30mg/m² twice daily.

Table 1:

Duration	Oral prednisolone dose (mg/m ² /day)	Maximum daily Prednisolone dose (mg)
4 weeks	60mg/m ² /day	60
If in remission at 4 weeks follow weaning schedule below		
4 weeks	40mg/ m ² /alt day	40
Then stop		

- 6.3 Prednisolone should ideally be given in the morning, and always with or soon after food. Always round the dose to the nearest 5mg to enable ease of dosing for parents.
- 6.4 If oral prednisolone is not tolerated, consider switching to IV methylprednisolone using the conversion rate 4/5 of the oral dose.
- 6.5 Ranitidine or proton pump inhibitor can be used if there are concerns about heart burn; however prednisolone given with foods is unlikely to cause an ulcer.
- 6.6 It is helpful for the future to note how long the child takes to respond to prednisolone (how many days until the first negative reading on urinalysis).
- 6.7 Will also need concurrent treatment of complications (refer to section; 11.0).
- 6.8 Expected outcome of new nephrotics:
- 24-month sustained remission rate of 49%;
 - Frequent-relapse rate of 29%.

7.0 Infrequent Relapse Protocol

- 7.1 If a patient is known to GOSH, check patient letter for individual relapse plan.
- 7.2 If symptoms are mild, including little or no oedema and child is otherwise well consider small dose of prednisolone to induce remission.

Table 2:

Duration	Oral prednisolone dose (mg/m²/day)	Maximum daily prednisolone dose (mg)
Until remission	30mg/m²/day	30
On 3rd day of remission wean to		
1 week	20mg/ m²/day	20
1 week	10mg/ m²/day	10
1 week	5mg/ m²/day	5
If on maintenance prednisolone continue on normal dose of prednisolone		

7.3 If there is significant oedema at presentation, or the oedema is worsening, or if no sign of response after 7 days, then should start or increase to:

Table 3:

Duration	Oral prednisolone dose (mg/m ² /day)	Maximum daily prednisolone dose (mg)
Until remission	60mg/ m²/day	60
On 3 rd day of remission wean to		
1 week	40mg/ m²/alt day	40
1 week	30mg/ m²/alt day	30
1 week	20mg/ m²/alt day	20
1 week	10mg/ m²/alt day	10
If on maintenance prednisolone continue on normal dose of prednisolone		

7.4 **Viral illness cover**

Small dose of prednisolone given during a viral illness reduces chance of relapse. (PREDNOS 2 study).

8.0 Frequently Relapsing

(Refer to Table 3)

8.1 Consider referring to Tertiary Nephrology. In the interim:

- **Prednisolone** 60 mg/m²/day, equivalent to 2mg/kg/day until remission;
- Maximum daily dose of 60mg;
- Once in remission wean according to the table 3 until the maintenance dose is reached. Remain on the maintenance dose for at least 6 months;
- If further relapse, **individualise** steroid wean as advised by the named consultant or GOSH and consider adjunct treatment as discussed below;
- If no relapse for 6 months, attempt to wean the prednisolone- **reduce dose by 5 mg every month**. If patient becomes dipstick protein positive during the weaning schedule return to previous dose and monitor for a full-blown relapse;

- If the patient relapses, start prednisolone at $60\text{mg}/\text{m}^2/\text{day}$ and then discuss weaning schedule with GOSH;
- If the proteinuria settles stay on present prednisolone dose, do not wean further.

8.1.1 If the patient continues to relapse then consider adjunct therapy with steroid sparing agents.

8.2 Prior to commencement of *any* secondary treatment:

- Assess adherence with steroid therapy;
- Base line investigations: FBC & differential, U&E, Liver & Bone profile, Magnesium, Lipids profile etc;
- At present Dr Cyriac starts the first line steroid sparing drug Levamisole locally but refer to paediatric nephrologist for second line drugs like cyclophosphamide, Ciclosporin etc;
- Treatment- induce remission with high dose oral prednisolone and then introduce steroid sparing agent.

8.3 Steroid sparing agents also to be considered if:

- Relapses on a maintenance prednisolone dose of $0.5\text{mg}/\text{kg}$ alt days / displaying steroid dependence;
- Concerns over linear growth;
- Intolerable side effects from steroid therapy;
- Poor adherence with steroid therapy.

9.0 Steroid Dependent

9.1 Consider referring to tertiary nephrologist:

- **Prednisolone** $60\text{mg}/\text{m}^2/\text{day}$, equivalent to $2\text{mg}/\text{kg}/\text{day}$ until remission;
- Maximum daily dose of 60mg;
- Wean steroid to maintenance dose equivalent to remission dose prior to onset of relapse;
- If the last successful dose is equal or more than $0.5\text{mg}/\text{kg}$ every other day, please mark the referral as urgent;
- Introduce steroid sparing agent. Treatment objective to achieve prolonged; remission and maintenance alternate day steroid dose $<1\text{mg}/\text{kg}/\text{day}$.

10.0 Steroid Resistant

10.1 If patient fails to go into remission after 4 weeks of daily, high dose steroid therapy contact GOSH to arrange a renal biopsy.

10.2 Consider poor adherence to steroid therapy.

11.0 Concurrent Treatment of Complications

11.1 Infective

- Varicella zoster immunity status should be checked at presentation and again, if immunity not established, before giving zoster immunoglobulin;
- In the event of chicken pox exposure within 3 months of high dose steroids or alkylating agents give Zoster immunoglobulin within 48 hours of exposure if not immune;
- **Measles** exposure within 3 months of high dose steroids or alkylating agents, give normal immunoglobulin if not immune;
- In the event of Varicella zoster infection administer ACICLOVIR according to age. Complications indicate admission for I.V. therapy.

11.2 Aciclovir

- 1 month - 12 years: 20mg/kg (max 800mg) 4 times a day for 5 days;
- More than or equal to 12 years: 800mg 5 times a day for 7 days;
- Reduce dose in renal impairment.

11.3 Immunisations

11.3.1 Highly recommend:

- Valent pneumococcal conjugated vaccine (Prevenar 13[®]), 3 single doses (0.5ml) by intramuscular injection, one each at 2 and 4 months of age. A third dose is given after the 1st birthday;
- Children aged 12 months to 5 years: two doses (0.5ml) with an interval of at least 2 months between doses. Not to be given for children over 5 years;
- All children over 2 years of age who have received the conjugate vaccine (PCV) need a single dose (0.5ml) of 23 valent vaccine (PPV) to provide protection against the serotypes of S.Pneumoniae not covered in the conjugate vaccine. Leave an interval of at least 2 months between the two vaccines;
- Children over the age of 10 years revaccinated.

11.3.2 Live vaccines should not be given to children who are on or have recently been taking immunosuppressive medication as defined below in point 11.3.3.

11.3.3 Immunosuppression in the context of immunisation is defined as any child who is receiving or has received in the last 3 months:

- Prednisolone 2 mg/kg/day for > 1 week;
- Prednisolone 1 mg/kg/day or equivalent for 1 month (i.e. 40 mg/m² alternate days);
- Lower doses of prednisolone combined with cytotoxic drugs;
- Long term lower dose immunosuppression.

11.3.4 Killed vaccines can be given but for best results once the child is taking $\leq 10 \text{ mg/m}^2$ alternate days:

- Encourage essential immunisations but advise of potential for relapse and inadequate immunogenic response to vaccination;
- Seek appropriate advice for other immunisations and foreign travel.

11.4 Severe Oedema and Ascites

11.4.1 **Assessment of hypovolaemia** -Hypovolaemia in the nephrotic state is a common but serious complication which increases the risk of thrombosis. Evaluation of hypovolaemia can be tricky and needs careful clinical assessment. Attending clinicians should correlate between daily intake output chart, daily weight checks and both blood and urine investigations. Clinical indicators of hypovolaemia include tachycardia, hypertension, cool peripheries and delayed capillary refill time. Laboratory parameters suggesting hypovolaemia include elevated urea or haemoglobin.

Recommendation to administer diuretics, Albumin infusion etc. need to be taken by senior paediatrician preferably after discussion with tertiary teams.

11.4.2 Diuretics without albumin must not be given in hypovolaemia due to the risk of thrombosis.

11.4.3 If hypovolaemia is severe (such as with noticeably cool peripheries, abdominal pain or elevated urea) then consideration should be given to treatment with intravenous albumin) and to thromboprophylaxis.

11.4.4 Oedema and ascites

A gentle fluid restriction is also usually beneficial to minimise oedema. Suggested fluid intake:

Less than 5 years = 750 ml;

More than 5 years = 1 litre.

A “no added salt” diet is recommended (refer to section 2.7).

11.4.5 Diuretics

These must only be used if severe and worsening oedema/ascites in the absence of hypovolaemia. Furosemide alone may be tried initially but if oedema is severe, the synergistic action of furosemide with spironolactone may be required. Doses are:

- Furosemide 0.5 – 1 mg/kg twice daily;
- Spironolactone 1 mg/kg twice daily.

11.4.6 If oedema persists, a thiazide may be added under the guidance of a consultant paediatric nephrologist. The thiazide of choice would therefore be bendroflumethiazide. The dose is:

- 2-12 years: 50-400 ug/kg once daily initially (max dose 10 mg), reducing to 50-100 ug/kg if prolonged use;
- 12-18 years: 5-10 mg once daily initially, adjusted according to response.

11.4.7 Albumin infusions

Albumin infusion is only indicated in symptomatic hypovolaemia or severe diuretic resistant oedema. It should be administered with great caution with frequent monitoring of vital signs until at least two hours after the infusion is completed. All patients needing an albumin infusion should be reviewed by the consultant and should be discussed with GOSH.

Dose:

- Shock = 4.5% albumin 20 ml/kg over 30-60 mins repeated if necessary. If volume status remains depleted, discuss with regional paediatric intensive care before giving further boluses;
- Mild hypovolaemia + oedema = 20% albumin 5 ml/kg (1g/kg) over 4 hrs with IV furosemide 1 mg/kg halfway and/or at the end of the infusion provided signs of hypovolaemia have resolved (mid and end-point clinical evaluation should be carried out);
- Severe diuretic resistant oedema = 20% albumin 5 ml/kg (1g/kg) over 4 hrs with IV furosemide 1mg/kg half way through infusion.

11.4.8 Risk of thrombosis

Thrombosis, either arterial or venous is relatively rare in the nephrotic state but the consequences can be devastating.

To decrease the risk of thrombosis:

- Avoid hypovolaemia;
- Prevent sepsis;
- Encourage mobilisation and avoid bedrest.

11.4.9 For children with prolonged nephrotic states, a history of thrombosis, or a marked hypovolaemic state (with elevated/rising plasma urea or haemoglobin) the following additional measures may be considered:

- Compression stockings;
- Low molecular weight heparin. Heparin is preferable to Aspirin for prevention of venous thrombosis but only available as sub-cutaneous injections. Enoxaparin is usually the LMWH of choice. It may be given through an Insufflon (changed weekly) to avoid daily sub-cutaneous injections. The prophylactic dose is 500 ug/kg twice daily (maximum dose 40 mg).

11.5 Antibiotic prophylaxis

Oral Penicillin V (125 mg twice daily if less than 5 years or 250 mg twice daily less than 12 years) may need to be prescribed to grossly oedematous/ascitic patients to protect against pneumococcal infection. There is no need for antibiotic prophylaxis for minor eye lid oedema or leg oedema. If peritonitis is suspected then cover for gram negative organisms is recommended until cultures are available.

11.6 **Gastro protection**

Despite large doses of steroids, few children experience gastritis symptoms. If necessary, children may be given ranitidine or omeprazole as gastro-protection whilst on high dose steroids.

11.7 **Hypertension**

Dynamap sphygmomanometer (commonly used locally) generally gives lots of false high readings. Please double check the blood pressure with manual sphygmomanometer before considering any antihypertensive management. Blood pressure readings taken at night when the patient is asleep using manual blood pressure instruments are considered most reliable and consistent.

Please liaise with paediatric nephrology team in Great Ormond Street hospital before commencing on any antihypertensive treatment.

11.7.1 Check volume status. If euvolaemic:

- Atenolol 0.5 – 1 mg/kg/day in single daily dose;
- Nifedipine (starting dose 200 – 300 μ g/kg three times daily);

11.8 **Ophthalmology** - Children on long-term steroids should have an annual eye check up with the a referral to the paediatric ophthalmologists if cataracts are suspected

11.8.1 **Dietary advice** - A balanced no added salt diet is recommended while the patient is in Relapse. The dietetic advice to achieve this is to avoid the addition of salt in cooking and at the table.

11.8.2 To reduce the intake of processed foods parents should select foods which contain less than 0.5 g Na per 100 g weight of food. This information is usually available on the packaging. Compliance with a no added salt diet will aid adherence to the fluid restriction and encourage good blood pressure control. The diet should be nutritionally balanced with an emphasis on healthy eating and the avoidance of a high saturated fat intake.

11.10 **Discharge planning**

Children will normally spend several days in hospital following a first presentation with nephrotic syndrome. Even if there is not significant oedema, a short admission will be necessary to teach children and their parents about nephrotic syndrome. For many children with their initial presentation, there is significant oedema and discharge date will be determined according to when the child is judged to be cardiovascularly stable.

11.11 Each day during their in-patient stay, children should have a thorough assessment of their fluid status including accurately completed fluid balance charts, regularly blood pressure monitoring and a daily weight. They should be examined daily for extent of oedema and signs of hypovolaemia.

11.12 Discharge checklist

Before discharge, parents/carers should know:

- How to dipstick the child's early morning urine and record this in a daily diary;
- How to recognise a relapse;
- Whom to contact for advice;
- Appropriate fluid and dietary advice;
- Steroid and immunosuppression advice.

12.0 Information and Support

12.1 Adequate information and often repeated explanation are essential.

12.2 There is an information leaflet available in the hospital intranet.

12.3 An illustrated booklet about condition and treatment is of great value and available from the GOSH website or the BKPA (<https://www.gosh.nhs.uk/conditions-and-treatments/conditions-we-treat/childhood-nephrotic-syndrome>) or Kidney Care UK (https://www.kidneycareuk.org/documents/39/5401_Kidney_Care_UK_KCFS017_Nephrotic_syndrome_factsheet_v3.pdf)

12.4 Referral to a paediatric community nursing service can help support families at home with reinforcement of info and monitoring of compliance.

12.5 Nursery/school liaison may be beneficial particularly for concerns regarding mood/behavioural changes and bullying.

12.6 Referral to a social worker and psychologist should be considered for children and families having particular difficulties.

13.0 Referral Centre

13.1 The Trust's referral centre is Great Ormond Street Hospital;

Tel. 0207 813 8305;

Please contact oncall paediatric nephrology registrar for advice, transfers etc.

Nephrotic Syndrome Specialist Nurse- Hazel Webb 020 7829 7829 or bleep 2263.

14.0 Further Local Follow up

14.1 Patients are generally followed up locally by Dr Cyriac. Please inform Dr Cyriac at the earliest to meet the family while inpatient.

14.2 On discharge parents are instructed to contact Dr Cyriac's Secretary at 01245 413266 if the child relapses or for any nephrotic syndrome related queries. As this is a stable condition PDAS cards (yellow cards) are generally not provided. However, parents may contact the ward staff if they have any clinical concerns out of hours or weekends.

15.0 Documentation

15.1 In all cases a set of hospital notes should be created.

15.2 Copy of all letters clinics should be filed in the notes.

15.3 Documentation should include the following:

- Medical history;
- Examination findings;
- Plan of investigations;
- Details of tertiary referral if made;
- Management;
- Flow sheet of results.

16.0 Staffing and Training

16.1 All paediatric and neonatal staff are to ensure that their knowledge and skills are up-to-date in order to complete their portfolio for appraisal.

16.2 Paediatric staff should be aware of the referral pathways.

17.0 Infection Prevention

17.1 All staff should follow Trust guidelines on infection prevention by ensuring that they effectively 'decontaminate their hands' before and after undertaking any patient contact.

18.0 Audit and Monitoring

18.1 Where a Patient's notes have demonstrated that the appropriate action has not been taken then a 'DATIX' form is to be completed. This will highlight further staff training needs.

18.2 A quarterly DATIX audit will be examined by the Lead Nurse and the Clinical Director and Risk Lead for CYP.

19.0 Guideline Management

19.1 As an integral part of the knowledge, skills framework, staff is appraised annually to ensure competency in computer skills and the ability to access the current approved guidelines via the Trust's intranet site.

- 19.2 Quarterly memos are sent to line managers to disseminate to their staff the most currently approved guidelines available via the intranet and clinical guideline folders, located in each designated clinical area.
- 19.3 Guideline monitors have been nominated to each clinical area to ensure a system whereby obsolete guidelines are archived and newly approved guidelines are now downloaded from the intranet and filed appropriately in the guideline folders. 'Spot checks' are performed on all clinical guidelines quarterly.

20.0 Communication and Implementation

- 20.1 Approved guidelines are sent via email to all paediatricians.
- 20.2 Hard copies of approved guidelines are kept in Phoenix Ward.
- 20.3 After approval, a copy of the guideline is published on the Trust intranet.
- 20.4 After these steps have been undertaken it is the responsibility of the individual staff member to update their knowledge of current research and guidelines as part of their continuing professional development.
- 20.5 Approved guidelines are published monthly in the Trust's Focus Magazine that is sent via email to all staff.
- 20.6 Approved guidelines will be disseminated to appropriate staff quarterly via email.
- 20.7 Regular memos are posted on the 'Risk Management' notice boards in each clinical area to notify staff of the latest revised.

21.0 Risk events / Error Reporting

- 21.1 All untoward events involving patient safety are reported to the risk management department by way of a risk event report form. This should be completed by the staff member(s) involved.
- 21.2 All errors are discussed at the monthly multidisciplinary meetings.

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Appendix 1: Preliminary Equality Analysis

This assessment relates to: Management of Childhood Nephrotic Syndrome

A change in a service to patients		A change to an existing policy	X	A change to the way staff work	
A new policy		Something else (please give details)			
Questions		Answers			
1. What are you proposing to change?		Full Review			
2. Why are you making this change? (What will the change achieve?)		3 year review			
3. Who benefits from this change and how?		Patients and clinicians			
4. Is anyone likely to suffer any negative impact as a result of this change? If no, please record reasons here and sign and date this assessment. If yes, please complete a full EIA.		No			
5. a) Will you be undertaking any consultation as part of this change? b) If so, with whom?		Refer to pages 1 and 2			

Preliminary analysis completed by:

Name	Dr Job Cyriac	Job Title	Paediatric Consultant	Date	22/01/19
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